On Becoming a Zebra
The Mastocytosis Chronicles
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On Becoming a Zebra

By Nicole Martinez, Psy.D., LCPC

“...In making the diagnosis of the cause of illness in an individual case, calculations of probability have no meaning. The pertinent question is whether the disease is present or not. Whether it is rare or common does not change the odds in a single patient. ... If the diagnosis can be made on the basis of specific criteria, then these criteria are either fulfilled or not fulfilled.” - A. McGehee Harvey, James Bordley II, Jeremiah Barondess

Zebra is the American medical slang for arriving at an exotic medical diagnosis when a more commonplace explanation is more likely. It is shorthand for a quote of the late 1940s by Dr. Theodore Woodward, professor at the University Of Maryland School Of Medicine, who instructed his medical interns: “When you hear hoof beats, think of horses not zebras”. Since horses are common in Maryland while zebras are relatively rare, logically one could confidently guess that an animal making hoof beats is probably a horse. This phrase continues to be taught to medical students. - Wikipedia 2015

Diagnosticians have noted, however, that “zebra”-type diagnoses must nonetheless

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be held in mind until the evidence conclusively rules them out. My journey almost 2 years ago or 28 years ago depending on how you look at it, but it feels like a lifetime. I am 40, and it was not until about 16 years ago that I started to have allergic reactions. I had allergy tests that pinpointed specific things I was supposedly allergic to, I had numerous urgent care and ER visits for severe allergic reactions for all those years. We made assumptions I was exposed to a certain allergen and added them to the list. As the years went on, the list of positive allergy tests grew and grew, but was I really allergic to these things, or did they have something in common?

Along with this came the debilitating fatigue, the extreme muscle, joint and bone pain, so we would add another diagnosis. I had constant strange blood test results indicating any number of disorders and diseases, so we would add a few more in, but never a certainty. I also always held the belief that it was not likely that I had numerous varied disorders, syndromes, and diseases, but rather one that explained it all. I was right, but it would take some time to piece it all together. I had a weak immune system, and everyone knew I was not kidding when I said I would catch what they had if they came near me. Who gets meningitis twice, pneumonia every other year, bronchitis often twice a year, and countless sinus infections? I do. It took someone to finally ask that question and not just treat the symptoms to figure it out. We figured out, after my eventual diagnosis, which I will be getting to, that I also had the added bonus of being born without immunities to HIB, pneumonia and meningitis. Many vaccinations, like a newborn, later, and I have an “adequate” immune system, just over the acceptable line.

So why do I say almost 2 years ago or 28 years? Well I have shared what the last 16 years looked like and grew to, and I will add my most recent diagnosis soon that will explain the time span. However the last few years have changed my life in every imaginable way. It was Mother’s Day, and I just had not been feeling right all day. I took my mother out to the Drake for Mother’s Day Afternoon Tea, a lovely treat. Throughout our day there I took my inhaler several times, and was just not feeling right. I was dropped off at home and walked through the yard to the house. I walked in, sat on my bed, and said to me husband, “I can’t breathe, take me to the ER.” Something I have never said. He rushed me there, and what proceeded was a sight that he says he will never forget. I went into anaphylaxis, had angioedema, giant hives, my throat was having bronchospasm and swelled shut. I was given any number of medications that were not helping. The ER attending called in someone from ICU. My husband sat helpless watching very concerned doctors struggling to stabilize me. They finally did, and I was admitted, for the first time of many to come. We found out that this day was the highest pollen count in history, and thought maybe that set it off. However, that did not explain the hives all over my arms for 6 days prior. In retrospect, I should have addressed that sooner. When I was released, I was told to go back to the ER if I even got hives.

Two weeks later, I have hives and
breathing issues, so back to the ER I go as instructed. This time I was treated as somewhat of a nuisance. Treatment for an allergic reaction and anaphylaxis, and an eye roll from someone who gave me a breathing treatment to the nurse, which of course they thought I did not see. I get it, you fixed the problem, and there are more dire cases to move on to. One week later, I was back to the ER with Anaphylaxis, swollen up and bright purple (a shade I did not think was possible from a person). The emergency meds worked, and I was given the option of admission or to go home with meds hours later. I chose home. Not even two weeks later, I was sitting in my office at work and swelled up like a pumpkin. I walked down the hall with my epi pen in hand and asked if it is as bad as I thought. An ambulance was called right away. I received some emergency treatment in the ambulance, and more at the ER. I was told within 20 minutes of arriving there that I was going to be admitted. This doctor seemed very interested in figuring out what was causing these life-threatening reactions, and admitted me and diagnosed me with an anaphylactic reaction on the side of the notes I could see. On the side I was not supposed to see, an implication was made that maybe I was giving myself something to induce the reactions. Really????? Because the mystery was not solved in our small window together, that must be the culprit. I still struggle with that knowledge to this day, and it breaks my heart for anyone else who was accused or discounted in this way.

One week later my life was changed again. We were living in fear of another reaction, and of the medications not working one of these times. A colleague asked if they could get my records and send them to a specialist in something called Mast Cell Diseases. I would do anything at this point, so I said please do. 12 hours later I was making the drive out of state to a specialty facility, 36 hours later I was seen by someone who promised me they would figure this out, and knew exactly what they were looking for. My husband and I cried at their certainty and reassurance. It had been a rough road. I spent two weeks there, had more tests than I can count, was diagnosed, and went home with a plan to stabilize me as much as is possible. I was connected with an amazing local doctor, and was their first patient with my disorder. They were amazing, and learned as much as they could get their hands on, and they still do. I feel in safe hands, and I know I am getting the right treatment.

Are there still drawbacks? Yes. I was sent for a consult, and without reading my records, the person immediately tried to prove I was not a Zebra. That I could not have what I have. This was all before reading my records and test results. Reading it changed things, but I still left in tears. It brought me back to the scary unknown times, to the one ER doctor, to fearing for my life, but I was reassured to let that all go by my main doctor. I would never have to see this person again. Did I mention they were citing 20 year old criteria that has been dramatically changed? However, even though I knew it was wrong, I could not bring myself to be the type of patient who says they know something their doctor did not.

In December, 2015, it was finally confirmed that I also had Postural Orthostatic Tachycardia Syndrome or continued on page 8
POTS. This is a secondary condition that those with mast cell diseases know well. I had been fainting, sometimes hitting my head, getting dizzy often, especially when standing up, or when being on my feet too long. This has been going on since Middle School, or 28 years ago. I had finally found a neurologist who not only took it seriously, but knew a great deal about mast cell diseases. He knew what he was looking at and for, and gave me the appropriate tests to verify it. This additional diagnosis is new, but I am adjusting and learning. He knew the symptoms I was experiencing with my form of POTS and MCAS before I even told him. It was comforting to see someone who knew what mast cell diseases were, and took one look at my records, and never questioned I had one.

I have to take a multitude of medications and treatments. One of the drugs that helps me the most is what is called an Orphan Drug. What is this? This is a drug that is not approved by the FDA, but is allowed to be brought in the country to treat Zebra's like me. It is brought in from Canada, sent to a pharmacy in Washington, where it is compounded, and then mailed to me. I of course must pay out of pocket for it, as it is not FDA approved. It is not FDA approved because not enough people have the disease to make it worth their while, and it has been used in other countries for 15-20 years, so the money making patents have expired. So no real motivation or incentive to approve it here. I now work from home, as I can best contain my environment; and I had flare ups too often to be fair to my employers, co-workers or clients. It remains a struggle to completely stabilize me, but I am much better than I was. My husband has been the most incredible person, but the life he thought we would have when we got married 4.5 years ago is very different. My life has completely changed, and that can be a lot to handle sometimes.

In medicine, the term “zebra” is used in reference to a rare disease or condition. Doctors are taught to assume that the simplest explanation is usually correct to avoid patients being misdiagnosed with rare illnesses. Doctors learn to expect common conditions. But some medical professionals seem to forget that “zebras” DO exist and so getting a diagnosis and treatment can be more difficult for sufferers of rare conditions. The road to diagnosis can be filled with anxiety, depression, hopelessness, and
anger. Mast Cell Diseases are considered rare conditions and so Mast Cell Disease sufferers are known as medical zebras. This identity has now been adopted across the world through social media to help bring our community together. Getting to know my community has been one of the most supportive, welcoming, and rewarding things to come out of this experience. We have The Mastocytosis (Mast Cell Disease) Society that is very active in research, has support pages and forums, innumerable resources, and holds an annual conference that doctors, patients, and caregivers can all attend. For many, this sense of community, and the support groups, are a lifeline, but sometimes they are not enough. Many patients need, and could greatly benefit from individual psychotherapy.

“There are close to 7,000 rare diseases that affect 30 million Americans (“About NORD”). “In the process of searching for a diagnosis, patients with rare diseases will find themselves in countless doctors' offices, often waiting years for a diagnosis and treatment. Healthcare professionals will most likely encounter patients with rare diseases on a daily basis, but the lack of knowledge of specific rare diseases makes many health practitioner-patient interactions frustrating, or even life-threatening if the medical professional is unaware of the severity of problems caused by a rare disease (Hull, 2014).” During this period, when a medical diagnosis has not been discovered, many of these patients are referred for psychological services, as many doctors will believe it is a psychological issue and not an organic one. This can be frustrating, humiliating, and shaming to the patient that is seeking help and an answer. I know it was to me the time it happened. We know our bodies, we know something is wrong, and we feel we have nowhere to turn.

So now therapists have patients looking for a diagnosis, failing to get a diagnosis, getting a diagnosis, and adjusting to major life changes due to their diagnosis. Patients often have a stronger interest in their diseases because “for patients with a rare disorder, the disease is no longer rare - it is a constant part of their lives and the life of their families” (Griggs et al., 2009). Medical problems that previously carried considerable mortality risk can now be managed more effectively. As a result, chronic medical illnesses have become more prevalent in recent years. With the increase in life expectancy comes a set of psychological challenges that face the chronically ill. Chronic disease is associated with high levels of uncertainty. Patients need to change their behavior as part of a new lifestyle of self-care. They also have to endure debilitating and demanding treatments. These are some of the factors that make adjustment to chronic medical illness psychologically demanding (White 2001). I was lucky enough to find a kind and intelligent man who educated himself on my health issues before we ever met.

It is generally accepted that around a quarter of patients with chronic medical problems have clinically significant psychological symptoms. In some cases, these psychological symptoms themselves are associated with physical morbidity. Even in the absence of overt psychological

“for patients with a rare disorder, the disease is no longer rare - it is a constant part of their lives and the life of their families”

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or psychiatric disorder, patients have to regulate often-complex and ever-changing thoughts, feelings, and behaviors (White 2001). This type of therapy is well suited for the chronically ill, and those with rare diseases, and it has been empirically proven to be effective. It can address the issue related to mood, fatigue, a general feeling of being physically unwell. It can help patients be more assertive advocates for themselves with healthcare professionals, to make sure they are being heard. This is an important piece, as many had a difficult time with this in the long road to diagnosis. A hallmark of the therapy is skill building to help the patient with disease management.

White (2001) discussed four essential components of the therapy, which still hold true today. They are: Agenda setting, self-monitoring, experimentation, and changing distressing thoughts. Agenda setting is encouraging the patient to make lists that are clear and focused about what they hope to cover with the physician during the visit. This helps to reduce frustration for the patient and the physician, it assures nothing important is left out, it provides structure to the appointment, and it helps you and the physician identify priorities and a plan.

Self-monitoring are tasks such as keeping a mood, medication and food journal. This can record fluctuations and issues that the patient might not remember amongst the many things they discuss in a check-up. This helps them to remember, and to see patterns. The types of monitoring assignments to be given could be endless.

Experimentation is when you ask the patient to try, track, and report back on situations and factors that might be exacerbating and flaring up their symptoms. For example, a fight with a family member or partner may trigger symptoms in the individual. If the connection is made, steps can be made to change the way they deal with things, or not put themselves in certain situations that are likely to have a bad outcome.

Lastly is the exercise of changing distressing thoughts. “Cognitive therapy usually involves the modification of thoughts and behaviors that seem to be contributing to a patient’s symptoms (White 2001).” The therapist can challenge their distressing thought and replace it with a healthier and more realistic one. This can have a profound impact on the patient’s well-being. I think it is clear that psychological services are not only effective, but are also essential to patients who are struggling for diagnosis, adjusting to a new diagnosis, or living with a chronic or rare illness.

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DANGEROUS KISSES

by Julie Skeldum

Oh, how I love to put my lips on you
But lately your sweet lips have become poisonous fruit
What can I do to escape your dangerous kisses
These ups and downs, all those near misses

This roller coaster we've been ridin' on
Fun for awhile, but I'm barely holding on
To you, and this storm we're rolling through
You look my way, and we don't know what to do

Oh, how I love to put my lips on you
But lately your sweet lips have become poisonous fruit
What can I do to escape your dangerous kisses
These ups and downs, all those near misses

Life seemed so damn easy before
The whole wide world came knockin' down my door
It throws me down, you pick me up
They say we're crazy, we just know it's love

Beaten down, feeling naked and afraid
All that's left to do is just cling to you and pray
Hot tears streaming like a river down my chin
The way it steals our lives should be a sin

You know I love to put my lips on you
This world around us has become poisonous, too
All I can do is taste your dangerous kisses
And hope most those hard times will somehow miss us

Cause I love your dangerous kisses
Oh, how I love your dangerous kisses

All I can do is taste your dangerous kisses
And hope most those hard times will somehow miss us
Spring Greetings! One month after attending the American Academy of Allergy, Asthma and Immunology (AAAAI) Annual Meeting in Los Angeles, I am still reeling from the enormity of the dedication I saw and felt from our esteemed physicians as they volunteered to give even more of their time to help establish a US network for mast cell disorders. This US network is a huge commitment, one that had been first discussed casually by several physicians here and there in the past after attending meetings of the European Competency Network on Mastocytosis (ECNM). TMS had long been encouraging the development of this network since we have so few centers here to treat patients. Dean Metcalfe, MD, from NIH/NIAID, co-moderated the 2015 TMS Challenges meeting at the AAAAI with Cem Akin, MD, PhD, from Brigham and Women’s Hospital/ Harvard/Boston Center of Excellence for Mastocytosis, and during that meeting Dr. Metcalfe strongly supported moving forward with development of the network, and physicians and industry partners present in the meeting all enthusiastically endorsed the idea. Susi Jennings, PhD, our Research Co-Chair who does an incredible amount of work for TMS, volunteered to coordinate the initial meetings to establish a committee to launch the network, working closely with allergists and hematologists throughout the last year, communicating with them by email, and keeping everyone involved and motivated. I salute you, Susi, for the hundreds of hours you spent on this, in addition to the many hours you and Research Co-Chair Nancy Russell continue to spend on data analysis of the 2010 Patient Survey.

At the AAAAI, our booth was hosted by Rick and Doris Hoopes, veteran volunteers who have an excellent way of gently inviting physicians and other health care professionals to come to the booth to receive educational materials on our TMS flash drive, prepared and shipped in advance along with other materials by Medical Conference/Education Chair Mishele Cunningham. This year, our booth placement was less than ideal, and we received much less foot traffic than usual as a result, something that we have addressed. Still, many physicians came and received educational materials and had their questions answered about mast cell disorders. The booth is a critical element in our educational initiative.

Susi attended the ECNM meeting in October, and prior to the formal proceedings, held a meeting for US delegates to the meeting to further discuss plans for a US network. Cem Akin, MD, PhD, and Jason Gotlib, MD, MS, from Stanford Cancer Center, agreed to co-moderate that meeting, and also, to Co-Chair the committee to establish the US Network on Mast Cell Disorders. We have received tremendous support from many of our European colleagues, who are eager to assist us in any way possible to make this network a success. Providing good care for patients with mast cell disorders in any part of the world ultimately benefits patients and families across the globe. Collaboration between the networks will be a goal.

Next came the American Society of Hematology Annual Meeting in December 2015 in Orlando. Once again TMS held its annual Challenges Meeting, and this time
Srdan (Serge) Verstovsek, MD, PhD, from MD Anderson, moderated. Jason Gotlib had also planned to moderate but had a scheduling conflict. He was able to join near the end of the meeting. Attending were physicians from the US and Europe who support the development of this network. Discussions centered on how the ECNM was established, and how individual centers within the ECNM were identified and incorporated into the overall network. Representatives from industry partners again were enthusiastic and excited about this opportunity to be involved in a US network.

In March 2016, we held the next TMS Challenges Meeting at the AAAAI in Los Angeles. This meeting had a different atmosphere from previous ones, and was more formal in structure, in addition to being the largest we have held. Rather than a brainstorming session, the attendees quickly settled down into discussing how funding for a network might be obtained, how other networks were formed, the process for centers to be admitted into the network, whether or not there would be a screening process and what it might consist of, postponement of establishing a TMS research-based patient registry (to be considered in the future as an integrated part of the network), and if and how centers would be monitored once part of the network. Experiences of centers in Europe were also presented. In addition to the main discussion, side discussions among smaller groups included talks about writing standards of practice for mast cell disorders before the network could be launched, and the need for careful review of other networks to see what has worked in the past, what is currently working and what we features we might want to incorporate into our network. Todd Wilson, DO, NIH, National Center for Advancing Translational Sciences, and Celeste Finnerty, PhD, TMS Research Committee, have offered to look into funding options. A website was also discussed as a core requirement for the network launch.

One issue that is very critical to me is that when discussing any funding support for this network, we must have a concrete long term vision for how we are going to sustain staffing these centers for the future. This means that any planning for grant applications will require that we put in for training programs for fellows to specialize in mast cell disorders. The logistics of this are tricky, and when I suggested to the group the possibility of obtaining funding in order to offer a third year, multi-center fellowship in mast cell disorders, several very valid obstacles were brought up. These included physicians drowning in school loans and being tired of fellowships by the end of their second fellowship year, continued on page 14
not able to sustain family life on another fellowship salary, which typically is under $50,000 per year, obtaining grant support for such a fellowship, and not having enough mast cell patients at any one center for the fellow to treat. Regardless of the obstacles that must be overcome, I feel strongly that, after looking around the table at these meetings, the majority of our dedicated physicians are mostly within 15 years of retirement age, and many are closer than that. If we do not come up with a sustainable plan now to generate interest and educational opportunities in becoming mast cell specialists, we will end up with a US network for mast cell disorders, but with no physicians to treat the patients in the future. It is absolutely critical that we create a plan to entice physicians in training to want to specialize in mast cell disorders, and that we create training programs for them to do so. I know this will cost lots and lots of money, but if we can obtain the grants now, and start training two fellows per year, in fifteen years we will have 30 new mast cell specialists. Can you imagine that many specialists here in the US?

As you can see, a lot of time and energy of the Board, Research and Education committee members has been involved in working on the initiative of a future US Network for Mast Cell Disorders. But that does not mean that we are neglecting our other duties as volunteers! I have been working with Quest diagnostics to see about getting a new CPT code assigned for the 11 beta prostaglandin F2 alpha test so that the test can be reimbursed at a higher level. Physicians in New York State contacted me because they are unable to order this test from Quest because the insurance companies will not reimburse adequately for it based on the current CPT code. We are in the beginning stages of a long process with this work, but we will persevere! This is such an important test for patients with mast cell disorders.

Meanwhile, we are full speed ahead for the 2016 TMS Annual Conference at the Wyndham Lake Buena Vista/Disney Springs in Orlando, FL on September 15-17. Sandy Johnson is our local host along with the Florida Support Group. She has already presented us with an amazing logo for the event! We have already booked several speakers, and are taking into consideration the many requests we have received from members to invite your personal physician. In the end, we create a program which has a balanced appeal to a broad audience, and which covers the major variants of our disease entity. If you requested a particular physician and he or she was not invited to speak, please understand that while we considered the many requests we received, we only have a total of 10 speaking slots, and we have to weigh the topics we selected for this conference and invite the speakers best suited to address them.

The Wyndham Hotel is beautiful and right across the street from Disney Springs, so there will be lots to do and many places to eat. We are planning a great program with lots of rest time interspersed with speakers, workshops, panel discussions and casual time for interactions in the evenings. We are doing a virtual walk again this year because it will still be pretty warm in Florida in September—too hot for masto families to walk or run a 5K! Look for an announcement about the launch of the Virtual Walk! We are asking every TMS member to raise something this year, even if it is a small amount. We will provide a sample letter for you to send to your family and friends asking for contributions. We have a lot to
accomplish, and we need your help to do it!

We continue with our advocacy work on Capitol Hill with Patricia Beggiato leading the way this spring. Patricia arranged for TMS to provide for donations of beverages for Rare Disease Day celebrations in Washington D.C. We are working closely with our new web design company to create a new website that will be innovative, up to date, informative and easy to navigate. We have invited many physicians to partner with us on providing the latest information for readers by writing short articles on a topic that we requested. As the articles are submitted, we have a team reviewing and editing them, submitting them back to the author for a final review before they are placed on the new website. We hope that this will result in bringing our readers a website that will continually be refreshed with new material by world renowned mast cell researchers.

We continue our patient advocacy and support by monitoring the TMS Facebook page, a huge job that takes many volunteers, a lot of patience and lots of time. Our Patient Care Coordinator nurses take calls when they are available from 9-5 pm daily, and communicate with hundreds of patients via email and private message. We have a new Volunteer Coordinator, Nikki Martinez, Psy.D, taking over from Sandy Johnson, who already has too many jobs handling the Chronicles and the 2016 Conference. Dr. Martinez is a psychologist who also works as a writer for the Huffington Post. We are fortunate to have her as our new Volunteer Coordinator, and many thanks to Sandy for the wonderful job she did establishing this position. If you would like to volunteer for TMS, please go to the TMS website, and fill out a volunteer application.

We urge you to look up support groups in your area and to join them. Reaching out to others with mast cell disease is a great way to manage your own symptoms and to share what you have learned with others.

As of today, we are still looking for a Treasurer for our Board. If you have accounting or CPA experience and would like to serve on the TMS Board, please contact me at chairman@tmsforacure.org. Thank you, and I hope to see you all in Orlando, where we will be having lots of fun!

Respectfully submitted,
Valerie M. Slee, TMS Chair
There is a great quote that many know by Vivian Greene, “Life isn’t about waiting for the storm to pass, it’s about learning to dance in the rain.” To me, this sums up the idea of living a balanced and full life while dealing with a chronic illness. It is about learning to acknowledge your limits, while still keeping your mind open to the possibilities that exist. This can be a very difficult task when living with a chronic illness and trying to navigate your limits.

It is not uncommon for individuals with chronic illness to blame themselves. It is not only the case that they think that they are weak, or a failure, but that society reinforces this fact for them. Society touts the idea of being strong: that individuals can overcome what they set their minds to. Because this idea is ingrained in the chronically ill, they feel “less than” their healthier counterparts and that they are somehow deficient when they can’t overcome what ails them.

One of the factors that makes this feeling worse is those who suffer with what we call “invisible illness.” Many people do not understand how sick and debilitated an individual can be, if it is not physically obvious. Too often people hear, “but you look fine,” when they are feeling terrible. This only reinforces their perception that they should be doing better than is possible. People with chronic illness and invisible disabilities are suffering; their suffering just might not be apparent to others. It is estimated that 10% of the United States population have medical conditions that could be considered invisible disabilities.

In order for the individual to both tend to their very serious health issues, and live the fullest life possible, many issues need to be addressed. First, the individual needs to accept their illness. By this I mean, accept that they have a very real and very serious medical condition, and there is absolutely nothing they could have done to prevent it. Anyone who has been sick for a length of time knows the hopes and often disappointments of the next promising treatment not working, the next specialist not having the answer, or not getting better as quickly as they had hoped.

Next comes gathering all the information they can to devise a well-rounded plan for optimum health. This entails acknowledging what they do and do not have control over in their life. They do not have control over the symptoms of their illness, but they can do some things to help control flare ups. Some of these factors include diminishing stress, eating clean and healthy, getting plenty of rest, and taking part in low impact activities. Perhaps most importantly, the individual must learn to grieve the life they had planned, and accept the life they have been given.
Often the person has to shift and adjust expectations they had for themselves, and for their lives. Maybe they will not be able to run a marathon, have children, or be a partner in the firm since they cannot put in 60+ hours per week. However, they can still accomplish many amazing things within their abilities. It is a matter of letting go of some things that may no longer be realities, and charting a more realistic course, which can still be full of wonderful goals and possibilities.

With this change comes the idea of letting go of being envious of others. It can be hard when you see someone accomplishing the things that you once wanted for yourself. When your friend has a baby, when your sister runs the city marathon or when your old co-worker gets the position that you were on the clear track for, it is easy to become envious. Envy and stress are counter-productive to health and take away the peace and hope the individual needs.

Another important issue is for the person is to distinguish their illness as part of themselves, but not their whole being. Many people “become their illness.” Their illness becomes their identity. It is ok for us to acknowledge our illness, while still saying that our illness does not define us. It is about acknowledging our limits, but redefining them as well. It is about forgiving ourselves when there is something we cannot do, as our intentions are what truly matters.

The Five Stages of Grief

Those struggling with a chronic illness often face difficult emotions in the wake of their diagnosis. Whether they realize it or not, they will inevitably go through a process of grief that wanders through five distinct stages.

First introduced by Swiss psychiatrist Elisabeth Kübler-Ross in her 1969 book, *On Death and Dying*, these five stages are defined as denial, anger, bargaining, depression and acceptance. While the vast majority of mast cell patients will live an average life span, the stages of grief are as applicable to the loss of a loved one as they are to the loss of a dream or an expectance of a “normal” way of living because of chronic illness.

Perhaps as you read these stages, you can identify with some of the emotions described. And you can realize that it is normal and even fitting to mourn the ending of a particular way of life, it is in the mourning of endings that you can find new beginnings.

**Stage 1: Denial**

Often a first reaction is denial. In this stage patients believe the diagnosis is somehow mistaken, and cling to a false, preferable reality.

**Stage 2: Anger**

When the patient recognizes they cannot deny their illness, they become frustrated. They ask, “Why me?” and “How can this happen to me?”

**Stage 3: Bargaining**

The third stage of grief leaves a patient hoping that they can avoid the cause of their grief. This is when patients change their lifestyle, hoping for a less serious outcome.

**Stage 4: Depression**

During the fourth stage, the patient despairs at the recognition of their mortality. They may become silent, refuse visitors and become sullen. They often ask, “what’s the point?”

**Stage 5: Acceptance**

In the last stage of grief, patients embrace mortality or their inevitable future. They become calm and stable even though they realize they cannot fight the outcome. They are able to say, “It’s going to be okay.”
Working Through Grief and Learning to Live with a Chronic Illness

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Most of the time, the people in your life will learn to know and understand when there are things you are unable to do. They forgive you, so it is important to have that same forgiveness and kindness of self. Another powerful tool can be the knowledge that while we may have our areas with which we suffer, so do many others. There can either be a connectedness to this idea, or an empathy that we develop for them. This empathy for others has a way of coming back on how we treat ourselves. Sometimes helping others who are suffering, ends up helping ourselves. Making even a small impact in the lives of others, or in advocacy of their condition, can have a positive impact on their emotional well-being.

Seeing an individual therapist and psychiatrist can have a positive outcome for the individual. They can attend weekly individual therapy sessions to address a number of issues. They can also concurrently see a psychiatrist to address any pervasive mood issues that could be helped with the proper medications. The two can work together as a team to develop an individualized and comprehensive treatment plan that attends to the overall needs of the chronically ill patient.

A therapist can help the individual deal with stress and learn the needed coping skills. As mentioned earlier, the therapist can help the individual define what they do and do not have control over. Once this has been defined, they can devise a plan of action to work on the areas they do have control over. This feeling and realization of control and the idea of forward movement in small, gradual steps, can be very empowering. They can work through the grief related to their diagnosis, and identify what it would mean to accept their health, but still move forward with their lives in a productive way.

Other issues that the therapist can help the individual with are related to the general theme of stress. An individual with a chronic illness is dealing with some significant stressors. Illness can often be unpredictable, no matter how many healthy strategies they put in place. While those strategies can lessen the impact, they do not stop a flare up from happening completely. The individual may have had to adjust to their “new normal,” and numerous life changes. Life changes might include financial changes and concerns, worrying about the quality of their life going forward and dealing with the physical symptoms that come along with their illness.

Individual therapy can help the individual navigate the negative realities and the positive possibilities that come along with living with a chronic illness. They can deal with their feelings of acceptance, envy, anger and hopelessness. They can determine what they have control over and what they do not. They can make a plan to lessen the impact of flare ups, how to connect with people in their community, and how they might be able to give back to others. The therapist can help them decide how to explain their illness to those in their life and what adjustments they need to make in their lives. Perhaps most importantly, the patient and therapist can work to adjust goals and expectations, so that the individual has reasonable and exciting things they are working towards. This can give a sense of hope, purpose, and control.
We asked: “What have you (or your loved one) lost due to your mast cell illness? And if you’re brave the follow-up question: How did you grieve your loss?” In light of chronic illness, all of us have experienced some form of loss. So here’s what you had to say about your losses and how you’ve handled them!

We hope these answers will help you know you’re not alone…and even give you some concrete ideas about how you can face your own losses and insert a little bit of hope into your life.

Lisa
I have lost my job of 26 years...my ability to leave my home due to chemical sensitivity. I am still in the grieving stage!

Michelle
I have lost my ability to play Tennis…something that I loved, which also included my entire social life. It may not seem that important to others, but it was a main part of my life and my identity. I used to play in college and went back to playing before I got sick. I was at the top of my women’s league and played every day then went to work. I could not look at posts about tennis or my friends or even look at my tennis racket. The way I grieved my loss is to try and find other activities such as painting reborn dolls. It has not replaced what I loved and never will, and I still have hope one day I can play tennis again and regain my friends and my old life!!!

Jennifer
I lost much. A career of 20yrs which included my capacity to multi-task, think quickly, retain codes and operate within multiple systems, to be a contributing member of society. I lost my sense of security in that I no longer had control over my body and breathing capacity. I lost the ability to easily accept invitations out to events & parties. I lost the ability to tolerate foods, scents, BBQs/grills, candles, chemicals, Febreeze, etc, reducing my environment to a very limited zone. I lost the ability to eat out at peak times when others do, even when I can tolerate a restaurant. I lost the ability to enjoy shopping due to piped in scents. I lost the ability to unwind with a glass of wine or enjoy a lovely martini! I lost a lot! So I grieved a lot. Not always in the best ways. But one must grieve! One must fall apart in order to pull themselves together again. To rebuild, replace, restore! It’s a two-sided penny. We have lost. But we’ve also gained. I take far better care of myself now than I did before. I have met incredible, inspiring people here who have helped me along my journey and touched me more than they’ll ever know. My husband and I are living “Team Family” on a deeper level than we ever could’ve imagined and are closer for it. I am stronger, wiser and more appreciative of this body that houses my soul. We could probably discuss what we’ve lost ‘til the cows come home!

Marktrina
I have lost my enthusiasm for life and my freedom of choices. I no longer have control of me. My mastocytosis has control of me.

Sally
I am still grieving. I lost my friends to not wanting to understand. I can’t go on vacations, can’t eat in restaurants or get take out. I am single and don’t date due to fear of rejection. I basically go to work and come home. The only positive in this mess is that I still have my family who keeps me

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Facebook Friends…
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strong with their love and understanding. I truly miss the “me” before all this started.

Linda
   We have lost the spontaneity and joy of most experiences in everyday life. I believe I’ve gone through every stage of grieving as I buried my old self and tried to like this new self. It is difficult to like this sick woman, this anxious woman, this tired woman, this cranky woman, the scarred woman. I have learned to try to focus on that it’s the illness and not me. I wish more people knew me before I got sick. I was a lot of fun. I had a photographic memory. I was the life of the party. I was smart. Well respected. I will grieve her loss forever. Now I meditate and do my best to keep my life as free of stress as possible. It helps to keep me grounded.

Lynn
   I lost my naivety believing that all doctors will take control of my health care and tell me appropriate next steps. I did not really grieve that type of loss, but had a long period of being stunned, and ultimately try to learn and share with others in my situation.

Jaeme
   We have completely lost going out of the house except for work. No family functions, no eating out, nothing fun at all, not even eating together at home at night. We used to love to cook together, but my husband has had to quit eating at night - this is when his idiopathic anaphylaxis happens. We just work or stay in the house. My husband hasn’t gone through all stages of grief yet…he is just stuck going back and forth between anger and depression. I just keep making sure all of the basics get done. He hasn’t agreed to see a therapist yet, as he will only see someone “who has gone through the exact same thing I have” (needle in a haystack). Oh, and tens of thousands of dollars in medical tests that didn’t show anything. But would pay ten times that for something that would help.

Jennifer
   I lost – am losing – a marriage over this disease, after so many doctors told me for years that this was “in my head” (despite the psychologists I saw and who evaluated me confidently believing otherwise) that even after it was finally diagnosed my husband refused to believe that it is real and affects me as much as it does.
   I lost my ability to have an independent career when my severe airborne allergies kicked in, and I had to be careful when in public. Before, I was working in arts

Jan
   I had to give up my nursing career that I loved so much. I grieved for a couple of years but seeing a wise therapist familiar with chronic illnesses has been very helpful.

Melanie
   My family and I have lost my spunk for life. Even though I put on brave smiles and do not try to complain, my old athletic, energetic self I have seen go down hill. As far as grieving, I have tried to embrace the different me, take things day by day and reaction by reaction, have faith and live my life the best and most positive I can for my family and myself.
management and community development, and currently I am trying to make it as a fine arts painter. It’s not working out well, as you can imagine.

I lost the ability to walk and even use my hands much when severe bone and joint pain caused by Mast Cell Disease triggers kicked in suddenly and flared my co-occurring Ehlers-Danlos Syndrome. It was a year of deep and uncontrollable pain before we discovered that my pain and joint dislocations could be controlled by antihistamines and avoiding triggers alone, and with enough antihistamines I don’t use my wheelchair, crutches, or joint braces and can resume most activity.

I periodically lose the ability to eat, to breathe normally, to think straight and plan ahead, to perform basic functions of life. In between, I appear mostly normal.

I approach my losses with a mixture of stoicism and very dark humor. I approached the grief head-on and waited a few months in that space until I knew I would turn it around with optimism, as I always eventually do. I worked through the grief in my painting. I worked through the grief for my children, and for all the women in my family who are finally receiving answers to their undiagnosed health issues thanks to my diagnosis. I worked through the grief because we are human, and this is just part of living... some of us are just a little unluckier than others in life, and it’s not anyone’s fault. It’s just luck. I’m still glad I’m here.

Susan

I lost my career, my freedom, some teeth, probably my ovaries, my retirement, and having a family. I have had this a long time, so I suppose I have an advantage of losing things slowly so it doesn’t seem that overwhelming most times.

Almost two years ago, in one six-week period about 10 people I knew died. Three of them were part of my close support system and had always supported and encouraged me, one of whom I planned to spend at least the next 20+ years with, so it’s harder now with them gone.

Knowing that all these things past things, not being able to travel to Nepal in my 20’s when I was living with a Nepali, no longer able to continue on my career path, I was a VP of a software company, miscarriages, teeth, etc...were not coincidences but actually part of this disorder sometimes gets to me. In general, I keep pushing on because the alternative, at least for me, is worse. It’s strange but I have hope, I am not sure why or for what, but I believe that things will get better. Medicine moves on. I find ways to get around obstacles. I still have friends. I can wear hats to cover my hair loss. I can smile. I can wear masks places. I never liked crowds so that is not a problem.

Meredith

I lost my career as a director of foster care. I lost my ability to go to large gatherings like concerts. I must prepare for anaphylaxis at all times so everything is an ordeal. I lost my children and also my grandchildren who don’t understand. Susan, thanks for saying teeth. I can only see the dental when Medicaid kicks in after $$$ as I must have an intubation team in the room with me. I have had extractions and can’t qualify to go back for a partial, so I have lost my desire for anyone to see me with few teeth and my smile. I used to be fearless. Now I have to think about everything. I even lost my reputation with this disease. I am still grieving.

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Lori

The things that were hardest to lose to mastocytosis were my last job of 15 years as an aide to special needs children, and my best friend. I went through several stages of grief for both. I miss the kids & being able to give of myself, watching their accomplishments on a daily basis, their sense of humor, comforting them, helping them learn new things both academically and socially. Maybe someday I will be able to find a way to do some of that again. That’s how I deal with that – hope.

My best friend says I “disappeared” from her life. That’s partially true. Many relationships cannot withstand the impact of Masto. It takes a bond and shakes it relentlessly to its’ very core; exposing every weakness and insecurity you have, and it hurts like hell. I learned to build a wall. Not a fortress, just enough of a fence to keep the riffraff out. And I’ve made new friends; some in the Masto community, and others not. This disease has taught me a few things, one being “Masto gives, as good as it takes.”

Deborah

The biggest thing I have lost to this disease is my independence. I have to eat, sleep, and take meds on a tight schedule. I have to limit, and in some cases eliminate, activities. My friends and family are making sacrifices due to a disease they don’t even have. I have made peace with my new life and traded my old life with a successful career for a life of harmony. I focus on living in harmony with this reality. I am at peace.

Pamela

I will comment on what my loved one has given up...my husband. He has given up scented everything, temperature control in our home, his own comfort over mine, wakeful nights when I am up and down because of reactions/not sleeping, doing all the yard work, often not sitting on our deck because I cannot, much of our social life, getting somewhere then having to leave, listens to my “Masto talk” when I am sure he has had enough of it, takes a shower after mowing/working in our yard, tells me he loves me and is in it for the long haul...no matter what. (No, he is not perfect, but I certainly am blessed, and I know it.)

Pam

I had to quit a job I loved, and I lost the ability to just leave the house and not think about every possible outcome. Most of the time it is just safer to stay at home. So I guess you could say I have lost my freedom as well. For several years I did feel “stuck” at home. Slowly I am coming around to thinking about the house as my sanctuary, rather than a prison. We have made a lot of changes to make it safe. Honestly I feel safest at home where the environment is controlled. I really do think our attitude plays a huge role in how we see our situation and ultimately how and where we find peace.
I remember the day clearly. As I walked to the car, a familiar phone number popped up on my caller ID. It was my physician’s office, and the nurse was calling with “news.” Now when most people receive a diagnosis, they have varied emotions. They may question the news. They may feel sadness or even despair. Or they could feel nothing...as they wrestle with what it all means. Not me. I was stoked! (According to the Urban Dictionary, that’s slang for “completely and intensely enthusiastic, exhilarated or excited about something.”)

Those of you who have struggled with undiagnosed health problems for years can identify with the overwhelming joy that comes with receiving an actual diagnosis. That day as I talked with the nurse and heard her read the doctor’s final diagnosis, I fell into the seat of my car, pumped my fist on the ceiling several times and eventually let tears stream down my face as I felt all the struggle of unknown illness fall away. For the first time in what seemed like forever, I had a glimmer of hope.

In his book, *The Anatomy of Hope*, Groopman, MD, writes about how patients facing acute or chronic illness have the power to impact their medical outcomes. Groopman defines hope as “the elevated feeling we experience when we see – in the mind’s eye – a path to a better future.” In the car that day, that’s what I had...a glimmer of hope that I could have a better future, knowing what disease process had a hold of me. I had hope that I could feel “better.”

While my initial hope has faded into more of a dance with my consciousness than the taking of a physical mountain, it’s what each of us need to be able to find acceptance and even renewed joy as we face illness. In light of living with a chronic illness, every single one of us needs hope. We need to know we are not simply a victim of our circumstances; we need to know we have power. We need hope.

How then, in the midst of facing daily distress due to illness, do we arrive at hope instead of depression or despair? Groopman suggests, “Hope can arrive only when you recognize that there are real options and that you have genuine choices. Hope can flourish only when you believe that what you do can make a difference, that your actions can bring a future different from the present. To have continued on page 24
hope, then, is to acquire a belief in your ability to have some control over your circumstances. You are no longer entirely at the mercy of outside forces.”

Ah...having real options and genuine choices is key to having hope.

When was the last time you felt you had real options and genuine choices in how you faced your chronic illness? I trust for many of you, it was today...even just a few minutes ago you made a choice that bettered your life. Yet for some of you...it has been a long time since you felt you had any real options to bring about a future different than your present. You feel stuck and unable to move. And you have lost hope. Groopman writes about you this way, “For many who cannot see hope, their vision is blurred because they believe they are unable to exert any level of control over their circumstances.”

It’s hard to be in this place.

For those stuck and unstuck in your journey toward hope, I offer you a thought: the truth of life is that we will all face undesirable circumstances. Some of us will be sick. Some will be in financial trouble. Some will face relational distress. Some will loose their jobs. Some will loose their homes. Some will loose loved ones. Problems and distress are a normal part of our lives; they are a part of our humanity.

It is in the moment we decide how we will react to our problems that hope can emerge or can die.

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It is in the moment we decide how we will react to our problems that hope can emerge or can die. Sometimes all it takes is one single moment to decide that our situation is unbearable and that there is no way forward for us to loose hope for decades.

But if in one moment we can loose our hope for a season, it is also true that in one moment, we can regain a sense of hope. All it takes is one idea or one shift in our thinking that allows for the thought that something, anything could be a little bit better. It’s not wishful thinking. Hope evaluates the obstacles and sees a way through. Groopman says, “True hope...is not initiated and sustained by completely erasing the emotions, like fear and anxiety, that are often its greatest obstacles. An equilibrium needs to be established, integrating the genuine threats and dangers that exist into the proposed strategies to subsume them.” In other words, hope sees the real dangers and finds a way to make life better anyway.

Hope doesn’t cure. It’s not a promise of a perfect body or a perfect life. It’s a real desire to make something better. Do we hope for a cure...YES! Because we know that medical science has over and over again found solutions to physical problems we believed would never be solved. It can happen. That hope is real!

So while you and I wait for a cure, we have a choice. Will we find a way to see the real dangers and obstacles of chronic illness and make life better in spite of our difficulties? Or will we decide all is lost? Daily, it is a choice.

When I received that diagnosis on the way to my car several years ago, I had the real-life knowledge that if I knew what I was fighting, I could work to make my life better. And I was right, in part. Unless a cure is found for what ails us, you and I will never be fully better. But even though I will still face the daily effects of my illness and I can’t do everything I used to, I can have a better life through small choices that matter to me. I have a different life than the one I imagined, but it’s still a life of my design. That’s what hope is all about.
Representatives of The Mastocytosis Society, Inc. (TMS) attended the December 2015 American Society of Hematology (ASH) and March 2016 American Academy of Allergy, Asthma and Immunology (AAAAI) Annual Meetings. During each of these meetings, TMS ran a booth in the Exhibit Hall, hosted Mast Cell Disorder Challenges meetings (see the “Letter from the Chair” and “2016 TMS Initiatives” in this Chronicles issue for more information) and met with a variety of specialist physicians and representatives from industry who have an interest in mast cell disorders. During the AAAAI meeting, we also attended the Mast Cell Disorders Committee and Lay Organization Breakfast meetings. In addition, there were a number of very informative medical and scientific sessions, and we tried to attend as many as possible while at these annual meetings, in particular, those related to mast cell disorders. Unfortunately, we were not able to attend all of the sessions listed below due to time constraints and conflicts. Some were also limited size sessions that have been repeated over the years and that we have previously attended, such that keeping space open for others to discuss mast cell disorders with specialists was a priority.

ASH Annual Meeting

Mishele, Wanda Hermann and Susi spent much of their time at the ASH meeting running our TMS booth or in meetings, but there were some presentations (both oral and poster) that were of particular interest. The web links noted below (which provide abstracts for the presentations listed) were functional as of the writing of this article.

The highlight session was Cytosis: Too Much of a Good Thing. “Cytosis” relates to having more than a normal level of a given cell type. Conditions involving eosinophils (Eosinophilia: A Pragmatic Approach to Diagnosis and Treatment by Amy Klion, MD), mast cells (Diagnosis and Management of Mastocytosis: An Emerging Challenge in Applied Hematology by Peter Valent, MD) and lymphocytes (Lymphocytosis, Lymphadenopathy: Benign or Malignant? by Jane Winter, MD) were discussed. During the mastocytosis session, there seemed to be about 500 attendees, and it was exciting to see so many physicians in a hall learning about mast cell disorders. All of these presentations are offered as written articles in the ASH Hematology 2015 Education Program (http://asheducationbook.hematologylibrary.org/). Unfortunately, although the table of contents and abstracts can be viewed, the articles contained in this program are not freely available to the public online. Hematologists who are members of ASH should have access and sometimes the public can gain free access to research and review articles at university medical libraries.

Erica Evans, PhD, from Blueprint Medicines, gave a presentation on the continued on page 26
pany's KIT inhibitor: Blu-285, a Potent and Selective Inhibitor for Hematologic Malignancies with KIT Exon 17 Mutations (https://ash.confex.com/ash/2015/webprogram/Paper80256.html). She described their studies characterizing the activity of this inhibitor using cell and animal models and noted that a phase 1 study of this drug would soon be starting in advanced systemic mastocytosis, which includes aggressive systemic mastocytosis, systemic mastocytosis with an associated clonal hematologic non-mast cell lineage disease, and mast cell leukemia (https://clinicaltrials.gov/show/NCT02561988).

Additional presentations (either oral or poster) related to mast cell disorders were also scheduled:

**Novel Functional Roles for Ten-Eleven-Translocation 2 (Tet2) in Normal and Leukemic Growth of Mast Cells** (https://ash.confex.com/ash/2015/webprogram/Paper86288.html)

**ASXL1 and CBL Mutations Are Independently Predictive of Inferior Survival in Advanced Systemic Mastocytosis** (https://ash.confex.com/ash/2015/webprogram/Paper79969.html)

**Additional Mutations in SRSF2, ASXL1 and/or RUNX1 Identify a High Risk Group of Patients with KIT D816V Advanced Systemic Mastocytosis** (https://ash.confex.com/ash/2015/webprogram/Paper80497.html)

**KIT D816V Mutation Positive Bone Marrow Mesenchymal Stem Cells in Indolent Systemic Mastocytosis Are Associated with Disease Progression** (https://ash.confex.com/ash/2015/webprogram/Paper78029.html)


**CCL-2 Is a KIT D816V-Dependent Modulator of Bone Marrow Remodeling and Microenvironmental Alterations in Systemic Mastocytosis** (https://ash.confex.com/ash/2015/webprogram/Paper83400.html)

### AAAAI Annual Meeting

Rick and Doris Hoopes did a fabulous job running our TMS booth, which freed Val, Celeste and Susi to attend various meetings and medical and scientific sessions. The AAAAI Mast Cell Disorders Committee spends time each year planning mast cell disorder-related sessions for the following annual meeting, and as in previous years, there were a number of sessions worth noting. As of this writing, the meeting program is still on the AAAAI Annual Meeting website (http://annualmeeting.aaaai.org/). Each year, the AAAAI puts out a Virtual Meeting containing videos of some of the presentations. Access to the videos can be obtained through the AAAAI for a fee (it takes a while for the videos to become available).

**Markers of Allergic Inflammation** (Session 1004), moderated by Dean Metcalfe, MD, included presentations by Lawrence Schwartz, MD, PhD *Allergic Inflammation: Value of Mast Cell Proteases as Surrogate Markers* and Sven-Erik Dahlén, MD, PhD *Lipid Mediators: PGD2/ LTC4/ D4*. 
**Masqueraders of Anaphylaxis** (Session 1006), moderated by Michael Frank, MD, and on the Virtual Meeting, had talks by Joseph Butterfield, MD (Familial Tryptasemia/MCAS) and Melody Carter, MD (Idiopathic Anaphylaxis). Dr. Butterfield spoke on a recently reported group of families where an association between inherited, elevated basal tryptase levels, connective tissue disorders and atopy (allergic reactivity) has been identified. He noted that these patients do not meet the criteria for mastocytosis and researchers are still working on identifying the disease mechanisms. Dr. Carter reviewed the symptoms and general criteria for diagnosing anaphylaxis, other diagnoses that may present like anaphylaxis and possible tests and procedures that can help in the diagnosis (including skin and serum-specific IgE allergy testing, anaphylaxis-coincident and baseline levels of serum tryptase, 24-hour urinary histamine metabolites and prostaglandin D2 (in urine, plasma or as urinary metabolite 9α, 11β-prostaglandin F2), peripheral blood for KIT D816V mutation and bone marrow examination). She also reviewed clinical and diagnostic features that can help distinguish between clonal forms of mast cell disorders (mastocytosis and monoclonal mast cell activation syndrome) and idiopathic anaphylaxis.

**Diagnostic Challenges in Mastocytosis: Serum Tryptase, Allele-Specific PCR and GI Pathology** (Session 1202), moderated by Catherine Weiler, MD, PhD, and on the Virtual Meeting, had presentations by a group of our well-recognized mast cell disorder specialists: Joseph Butterfield, MD (My Patient Has Elevated Tryptase. Now What?), Dean Metcalfe, MD (KIT Mutational Analysis: Allele-Specific PCR), Cem Akin, MD, PhD (Mast Cells in the GI Tract: Is It Mastocytosis?), Alberto Orfao, MD PhD (Value of Flow Cytometry in Diagnosis of Mastocytosis: Advantages and Pitfalls) and Patrizia Bonadonna, MD (Hymenoptera Anaphylaxis: When to Suspect Mastocytosis?). This was a great session and I’m very thankful that it will be on the Virtual Meeting because, despite the large number of seats available, it was not very well attended. A concurrent session on Allergen Immunotherapy, Today and Tomorrow, a very popular topic, was a huge draw in the next hall and had standing room only.

Dr. Butterfield reviewed clinical conditions where elevated serum tryptase levels have been identified, and when and how physicians should suspect and evaluate for a mast cell disorder. He also pointed out that even though a baseline level above 20 ng/ml is one of the criteria used to make a diagnosis of systemic mastocytosis, no specific level of tryptase rules out the possibility of a mast cell disorder. If tryptase levels are elevated after a reaction, tryptase should be tested 24 or more hours after the reaction to obtain a baseline level. Knowing these two levels will allow for a calculation to determine whether or not a mast cell activation event has occurred. This calculation is done by multiplying the baseline level of tryptase by 1.2, and adding 2 to that number. If the serum tryptase measurement after the reaction is greater than the result of the calculation, then a mast cell activation event has occurred.

Dr. Metcalfe noted that in adults, if mastocytosis in the skin is found, chances are high that the patient has systemic mastocytosis. A more sensitive test for the KIT D816V mutation (allele-specific
PCR, with a sensitivity of 0.01% that can be performed in peripheral blood samples has been developed, but is not yet widely available here in the US. [Mayo Clinic in Rochester, MN can perform the test (http://www.mayomedicallaboratories.com/test-catalog/Overview/88802) and there are a few other labs in the US that may also run it). This test is different from the KIT “sequencing” test. Dr. Metcalfe noted that currently in the US, the result is often reported as either positive or negative, although in a research setting, results can be presented in more detail as an “allelic frequency”, which is basically a measure of the extent to which the mutation is present versus KIT without that mutation. Receiving a negative test does not rule out a mast cell disorder.10, 11 If an adult with systemic mastocytosis does not test positive for the KIT D816V mutation, then sequencing of KIT might be considered. Dr. Metcalfe also showed tests to consider if a child or adult is suspected of having mastocytosis.

[Some comments about KIT D816V testing: As noted above, the allele-specific PCR test has a sensitivity of 0.01%. The Mayo Clinic webpage listed above for this test explains this sensitivity level as follows: “0.01% or greater of the KIT alleles present in the specimen must contain the mutation to be detected by the assay”. By contrast, there is a “KIT D816V Mutation Analysis (Mastocytosis)” test performed by Quest Diagnostics, where a method called “PCR-based pyrosequencing” is used to detect this mutation. This particular test has a sensitivity of 2%, such that it detects the D816V KIT mutation if that mutation is 2% or more of the alleles present in the sample, so it is not as sensitive a method as the allele-specific PCR. Due to the improved sensitivity, the allele-specific PCR test for KIT D816V can be performed in blood samples. However, the Mayo Clinic webpage for the test does caution the following: “Some systemic mastocytosis cases may have the mutation only in mast cells. Since these cells rarely circulate in blood and are difficult to obtain in significant numbers from bone marrow aspirate specimens, false-negative results may occur if neoplastic cells are present below the sensitivity of the assay (fewer than 0.01% mutated alleles).” The Mayo Clinic page also notes that test results are presented as either positive or negative, such that the test is not reported as an allelic frequency.]

Dr. Akin reviewed gastrointestinal (GI) and other symptoms in mastocytosis and noted that all forms of mastocytosis, including cutaneous, can cause the patient to experience GI symptoms. If an endoscopy is performed due to suspected mastocytosis, “multiple, systematic random biopsies of different regions of the colon” should be taken, along with biopsies of any areas that appear abnormal because this can help offset the difficulties sometimes seen in making a diagnosis using GI biopsies; mastocytosis in the GI tract is often subtle and focal and can be easily missed. The presence of eosinophilic disease can also hinder identification of mastocytosis. Analyzing samples for KIT (as tryptase staining is not always present in GI) and CD25 can help identify mastocytosis, where mast cells may be seen in aggregates of 15 or more cells. Although the presence of spindle-shaped mast cells in bone marrow is a minor criterion in the diagnosis of systemic mastocytosis, the presence of spindle-shaped mast cells in the GI tract is not necessarily abnor-
Dr. Akin discussed results of a study comparing GI biopsies from patients with systemic mastocytosis, irritable bowel syndrome and those without GI symptoms, highlighting the difference between increased numbers of mast cells and the presence of abnormal mast cells. Dr. Orfao explained that activating KIT mutations lead to an expansion and accumulation of mast cells in tissues and that over 90% of patients with SM have such a mutation (KIT D816V is an example). Abnormal mast cells are often spindle-shaped, can have a hypogranular cytoplasm and abnormally shaped nuclei, in addition to certain surface markers, such as CD25, that are not present on normal mast cells. The maturation stage of a mastocytosis patient’s abnormal mast cells (whether the cells are immature, mature, mature but resting, or are activated), determined by analyzing mast cell surface markers, correlates with different mastocytosis disease categories and prognosis. He also talked about how the types of cells that contain the KIT mutation (only in mast cells, or in mast cells, along with other myeloid and/or lymphoid lineage cells) can relate to prognosis and spent some time discussing the differences between acute and chronic mast cell leukemia.

Dr. Bonadonna said that insect sting anaphylaxis was responsible for 20% of all anaphylaxis-related deaths in the US and is the most common trigger of anaphylaxis in mast cell disorder patients. She pointed out that for patients who experience severe hymenoptera venom anaphylaxis, those who present with severe hypotension without hives/angioedema should be considered for evaluation for a clonal mast cell disorder (systemic mastocytosis or monoclonal mast cell activation syndrome), regardless of their baseline level of serum tryptase. Also, it is recommended that patients with a clonal mast cell disorder and severe reaction to venom receive life-long venom immunotherapy.

Managing Stinging Insect Allergy in the 21st Century (Session 2306), moderated by Dennis Ledford, MD, and on the Virtual Meeting, included presentations by David Golden, MD (Initiation and Discontinuation of Venom Immunotherapy: How Long is Enough?) and Mariana Castells, MD, PhD (Anaphylaxis after Hymenoptera Sting-Overlap with Mast Cell Disorder).

Identification of a Mast-Cell-Specific Receptor Crucial for Pseudo-Allergic Drug Reactions (part of Session 3704) will be on the Virtual Meeting and was presented by Xinzhong Dong, PhD. Dr. Dong discussed a surface protein, found on both human and mouse mast cells, that is essential for IgE-independent mast cell activation by certain drug triggers, including dyes used for imaging. He noted that a collaboration exists with a pharmaceutical company to develop a blocker of this molecule, with the intent to inhibit mast cell activation caused by such drugs.

The remaining mast cell disorder-related sessions were ticketed, interactive discussions limited to 30 people and are not available on the Virtual Meeting. These sessions offer attendees the opportunity to ask specialists more specific questions related to the topic being discussed.

Allele-Specific PCR to Diagnose D816V+ Clonal Mast Cell Disorders (Session 2507) continued on page 30
was moderated by Cem Akin, MD, PhD, and Dean Metcalfe, MD. Drs. Akin and Metcalfe discussed a sensitive test, allele-specific quantitative PCR for the presence of a D816V mutation of KIT, which can be performed in peripheral blood and bone marrow.\textsuperscript{10,11} They noted that a negative test does not rule out mastocytosis. Although a positive test indicates the mutation is present, a negative test may mean that there are not enough cells with the mutation to be detected. Further comments regarding this test were noted above for Dr. Metcalfe’s presentation on the topic.

**Mast Cell Activation Syndrome(s): Diagnosis and Treatment** (Session 3001) was moderated by Mariana Castells, MD, PhD, and Lawrence Schwartz, MD, PhD. This session was held at the same time as the Mast Cell Disorders Committee meeting, so we were unable to attend it.

**Mastocytosis in the Young Child: Diagnosis, Management and Prognosis** (Session 3506) was moderated by Melody Carter, MD, and Dean Metcalfe, MD. The specialists mentioned that they have not had problems with vaccines with their mastocytosis patients, but that physicians should be careful not to administer a vaccine through a skin lesion, because this could cause a reaction to occur. If a child with mastocytosis has hepatosplenomegaly, a bone marrow biopsy should be performed, as the child is likely to have systemic mastocytosis. If a child does not have hepatosplenomegaly, lymphadenopathy or peripheral blood abnormalities, a bone marrow biopsy is generally not performed and the child is followed with clinical exams, tryptase levels and testing to determine if an activating KIT mutation is present. Dietary management was also discussed. One of the main take home messages was that elimination of broad categories of food should be discouraged (e.g. high histamine foods) and that most mast cell patients can be effectively managed by eliminating only foods to which patients have reacted. Otherwise, nutritional deficiencies may result. The following reference includes a study of the clinical disease course for a group of children with cutaneous mastocytosis.\textsuperscript{19}

**Mastocytosis Mimics: Cutting Through the Clutter** (Session 4706) was moderated by Joseph Butterfield, MD, and Todd Wilson, DO. We’ve attended this session in the past and it has covered other possible diagnoses to rule out during an evaluation of a patient suspected of having mastocytosis, as well as testing that should be performed to evaluate the patient for mastocytosis.

Definitions, criteria and global classification of mast cell disorders with 
special reference to mast cell activation syndromes: a consensus proposal. 


There’s an App for that!
Find Apps That Help You Cope With Chronic Illness

Would you like to use your cell phone to help you improve the way you handle your thoughts and emotions? There’s an app for that. Here are two we found promising. (As always, please consult your physician with medical questions, problems or before making significant health-related changes. In addition, if you are having a serious thought-based crisis, like suicidal thoughts, please seek help at the nearest emergency room.)

**MoodKit**
CNET says Moodkit (iPhone, $4.99) is “like having your own portable psychologist…packed with tools designed to improve not just your mood, but also your overall well-being.” This app offers 200 activities to choose from plus a journal that prompts you with questions to help you archive your thoughts. It is designed to help you take action to improve your life, feel better by changing how you think, rate and monitor your mood progress and develop self-awareness and healthy attitudes.

**Happify**
This app helps you manage and improve your emotional health. The first time you open Happify, you’re prompted to select a track that best meets your needs such as finding more “me” time or getting better at handling stress. Each track is designed by an expert using the latest scientific research and is full of quick, daily activities to help you learn successful habits.

Have a favorite app? Email us at editor@tmsforacure.org, and we may share it in a future edition of The Chronicles!
We're looking forward to our annual conference to be held September 15-17, 2016. This year, the conference is being hosted in Orlando, Florida right next to Walt Disney World! The annual conference is an opportunity to learn more about this illness from physicians who have studied mast cell issues and published their research. And one of the highlights of the conference has always been the chance you have to meet others who have a mast cell illness, to learn their stories and to make life-long friends.

The Mastocytosis Society, Inc, cordially invites you to attend our 22nd annual meeting being held in Orlando, Florida. Join mast cell disease experts, the Board Of Directors, patients and their families for a one of a kind 2-day conference.

Program Goals: This program is for patients, caregivers, physicians, nurses, and anyone interested in learning about mast cell disorders. Our goal is to present introductory and updated material in a relaxed, interactive environment that will maximize learning.

Hotel Information: The conference is being held at the Wyndham Lake Buena Vista Resort located at 1850 Hotel Plaza Blvd, Lake Buena Vista, Florida. TMS has secured a conference rate of $124/night plus taxes and fees. This special rate can also be secured for 3 nights before and after the conference in case you would like to stay and enjoy the Disney Parks. To make your reservations please call: 1-800-624-4109 and tell them you are with “The Mastocytosis Society Annual Meeting”. All rooms must be booked no later than August 24th. You may also book your room online at: http://wyndham.com/groupevents2016/MCOLB_MASTOCYTOSISSOCIETY/main.wnt

Please note there is a resort fee of $5.00 per night. This fee is usually $20.00 per night, but TMS was able to negotiate a discount on participants’ behalf. Resort fee covers: high speed internet for unlimited devices, transportation to Disney theme parks, newspaper and use of all resort activities.

Airports: Orlando International Airport (MCO) is just 17 miles from the hotel. Orlando Sanford International Airport (SFB) is 43 miles from the hotel. There is no complimentary shuttle service, Taxi service, Super Shuttle, and rental cars are available at both airports. Mears Transportation and Go Airport Shuttle service offer competitive fees. Please reserve shuttle service ahead of your trip.

Parking: There is plenty of onsite parking. You may self park or valet-park. Cost is 8.00/day.

Children’s Room: We have secured a room close to the conference room with toys and activities available for children of all ages. A parent, grandparent, or responsible adult must accompany the child at all times in the room to supervise them and attend to any medical needs. There will be a couch, refrigerator, DVD player, TV, and many activities for the children. We are planning on live streaming the doctor presentations via Go To Meeting for the caregivers in the room if they desire. You must bring your laptop for this purpose. Pre-registration of the children is a necessity. Please note the conference registration fee includes the meals listed, use of the children’s room, and the streaming of the video.

Raffle and Silent Auction: TMS accepts donation of gift cards, new items of interest to mast cell disease patients, books, jewelry, kid’s items, themed baskets, and any items appropriate for a silent auction.
or raffle. Remember that people travel by air, and to not send large items. Raffle tickets are sold throughout the conference, and silent auction items will be displayed and available for bidding. Credit cards, cash and personal checks accepted.

**Disney Parks:** Disney World includes four main parks: The Magic Kingdom, EPCOT, Hollywood Studios and The Animal Kingdom. Additionally, two water parks and the Disney Springs shopping and dining district are all centrally located. The conference hotel runs a continuous shuttle service every 30 minutes to all of the Disney parks, beginning one hour before the parks open and lasting two hours after the parks close. An evening shuttle to Disney Springs is also available. If you plan to visit a park before or after the conference, you can purchase tickets on Disney's website or at the hotel ticket kiosk.

**Temperatures:** The sun will likely shine each conference day. The average temperatures can reach highs in the upper 80's and a lows in the lower 70's. Most afternoons, a short rain shower will pass over. And humidity will average about 60%. If you're impacted by heat, don't worry – the conference hotel has great air-conditioning. And people in Orlando are accustomed to staying indoors when the temperatures rise. If you're concerned about heat, you can always try methods the locals with Masto employ: cooling vests for the hottest times of the day, drinking iced beverages when moving from place to place outdoors, wearing sun-protective clothing or using a sun-protective umbrella.

I cannot attend the conference, so how can I get involved? If you cannot attend, you can help in two ways! First, you can join our virtual walk-a-thon team and help raise funds for TMS. Second, you can send donations to the TMS conference silent auction or raffle. See more information in this issue about both options. Every single donation to the walk-a-thon or the auction and raffle makes a huge difference in funding our initiatives.

**Other Important Issues:** This conference is a scent free conference. Please refrain from wearing any scented perfumes, after shaves, hair sprays, or body sprays/lotions. Please refrain from using scented shampoos, conditioners or body wash. Please plan ahead. That being said patients with mast cell disorders are unique, and one may have to search a long time to find a shampoo that does not trigger a reaction. Please do your best to use scent free products. If you are odor sensitive, please bring a vogmask or similar protective device. TMS cannot guarantee a completely scent free environment. While at the conference if you have a problem with a smell, please move to safety and notify a TMS Board Member.

**Dietary Issues:** TMS works hard too provide a menu with a wide range of foods, including gluten free, dairy free options, and nut free. If you have specific dietary needs beyond these, please bring your own food. A refrigerator has been provided in each guest room to help accommodate participants. If you have specific airborne allergies to a food, please fill in the area on the conference registration form and include a phone number and a committee member will call you for more details.

**Healthcare Issues:** Please note that if you have any health care needs, or may be in need of medical assistance, you must travel with a knowledgeable companion. TMS is not licensed to provide any health care, direct patient care, to administer medication, or make medical assessments. Although our speakers are physicians and experts, they are not licensed to practice health care in Florida. Please do not rely on TMS staff or its speakers in a medical emergency.

**Speakers:** Many of you came forward asking that your private physician be allowed to speak at the TMS annual meeting. The TMS Research Committee and Board of Directors considered each request. Physicians not chosen to speak will be considered for future conferences.
Conference Program and Schedule
Please note: the schedule is subject to change. Speakers are not guaranteed.

Thursday, September 15th Evening- Main Ballroom
6:00-7:00  Early registration and Meet and Greet with Board of Directors
7:00-9:00  Question and Answer Session

Friday, September 16th Morning- Main Ballroom
7:30-8:45  Registration and Full Breakfast. Mast Cell Primer Video (optional)
8:45-9:00  Welcome and Opening Remarks Sandy Johnson and Valerie Slee
9:00-9:30  Theoharis Theoharides MD, Ph.D: Adult Cutaneous and Indolent Systemic Mastocytosis
9:30-10:00 Joshua D. Milner MD: A New Triad
10:00-10:15 Break: Snacks Provided
10:15-11:00 Theoharis Theoharides MD, Ph.D: Neuropsychological Aspects of Mast Cell Disorders
11:00-11:30 Celalettin Ustun, MD: Mast Cell Disease, Aggressive Variants
11:30-11:45 Update on Tyrosine Kinase Inhibitors
11:45-12:30 Q and A with the Speakers

Friday September 16th Afternoon- Main Ballroom
12:30-2:00 Lunch on your own
2:00-3:30 Support group breakout sessions. Each group will be in a private session, please attend the proper group
Patients: led by Rita Barlow and Nikki Martinez
Caregivers: led by Patricia Beggiato, Casey Cunningham, Andrew Slee
Children: led by Valerie Slee
Patients with advanced disease: Dr. Ustun; Mishele Cunningham
3:00-3:15 Break- Snacks Provided
3:30-4:15 ER Protocol- filling out your paperwork
4:15-5:00 Anaphylaxis- What you need to know and when to go to the ER

Friday September 16th Evening- Poolside
7:00-9:00 TMS sit and chat poolside, completely optional, snacks provided.

The Mastocytosis Society P.O. Box 191752 Atlanta, GA 31119
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Conference Program and Schedule
Please note: the schedule is subject to change.
Speakers are not guaranteed.

Saturday September 17th Morning- Main Ballroom
7:30-8:30  Registration and Full Breakfast
8:30-9:00  Annual TMS meeting open to all members
9:00-9:30  Mariana Castells, MD, Ph.D: Mast Cell Activation Syndrome
9:30-10:00 Matthew Hamilton, MD: GI Manifestations of Mast Cell Disease
10:00-10:15 Break: Snacks Provided
10:15-10:45 Roberta Zanotti MD: Bone Loss in Mast Cell Disease
10:45-11:15 Mariana Castells, MD, Ph.D: Pediatric Mast Cell Disease Variants
11:15-12:00 Q & A with the Speakers

Saturday September 17th Afternoon- Main Ballroom
12:00-1:30  Lunch on your own
1:30-2:15  Nikki Martinez Psy.D.,LCPC: Stress Related to Mast Cell Disease
2:15-3:00  Bonnie Nasar, RDN: Nutrition and Mast Cells, with Q and A
3:00-3:15  Break: Snacks Provided
3:15-3:45  Gianina Hayes, Ph.D: From Misdiagnosis to Prognosis
3:45-5:00  Support Groups- Disease Specific
            Cutaneous Disease- Mishele Cunningham
            MCAS and Pediatric- Dr. Castells and Valerie Slee
            Systemic Mastocytosis- Dr. Zanotti and Dr. Theoharides
            Gastrointestinal: Dr. Hamilton and Dr. Glover
            General Support Group- Rita Barlow, Nikki Martinez, Bonnie Nasar
5:00-6:00  Rest up for an exciting evening

Saturday September 17th Evening
6:00-6:30  Bid on Silent Auction items, have a cocktail at the cash bar, mix and mingle.
6:30-9:00  Buffet style dinner served. Silent auction winners announced and raffle ticket drawings. The cost of this dinner is included.
Registration Form Directions: Please complete all sections and calculate fee. Mail this form along with a check for payment in full to:
The Mastocytosis Society
P.O. Box 191752
Atlanta, GA 31119

Name:_________________________________________________________________________________________________

Address:________________________________________________________________________________________________

City:____________________________________________________________ST:_____________ZIP:________________________

Phone:_______________________________________EMAIL:_______________________________________________________

Additional Attendees Names: if more space needed please use back of this sheet

Adult:_____________________________________________________________________________________________

Adult:_____________________________________________________________________________________________

Child:_____________________________________________________________________________________________Age:________________________

Child:_____________________________________________________________________________________________Age:________________________

Please note any airborne food allergies:_____________________________________________________________

Registration- one membership fee per household, entitles everyone in the household to pay member pricing. If you are a member, leave that blank.

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The Mastocytosis Society P.O. Box 191752 Atlanta, GA 31119
22nd Annual Conference Scholarship Information
September 15-17th 2016 Wyndham Lake Buena Vista,
Orlando, Florida

Scholarship Description
Partial and full scholarships are available to those who need financial assistance in order to attend the annual conference. Submission of an application does not necessarily guarantee a scholarship. Applicants who have not received a TMS conference scholarship within the past 5 years will be given priority. Applications remain confidential, and recipients will be notified by August 1st. To determine eligibility and apply for a scholarship to help you and/or your immediate family attend the 22nd Annual TMS Conference, please complete and submit the following form.

Please note that you will be required to book the hotel room on your credit card under your name, and that TMS will reimburse you for your room via check on Saturday of the conference. Conference fees will be paid for by TMS. The completed and signed form must be received by TMS no later than July 15th.

Applicant Information (Please list each person to be covered by this scholarship)

Names: _________________________________________________________________________

Address:_______________________________ City:_________________________ST: ______

Zip Code:_______________ Phone (cell):_______________________(home):_____________ 

Email:_______________________________________________________________________________

Total number of adult scholarships:___________ Children: _____________ Ages:__________

STEP 1: Please check each of the following to ensure qualifying criteria are met:

___ I am a current TMS member.

___ I have a financial need, which qualifies me to request a scholarship to attend the annual conference.

___ I have not received a TMS scholarship within the past five years. OR I received a TMS scholarship to attend the annual conference within the past five years (circle: 2011, 2012, 2013, 2014, 2015)

___ I understand that scholarship funding is limited and applicants who have not received a scholarship within the past five years will be given priority.

STEP 2: Please select the option that applies to your situation:

___ I am willing to accept a scholarship offer equal to the current TMS member conference registration fee of $200.00

___ I am in need of a scholarship offer of more than $200. I am willing to accept a scholarship offer equal to the current TMS member conference registration fee plus the cost of 3 night’s accommodations at the Wyndham Lake Buena Vista. Currently available is: $ 124/night 2 Queen beds, per night plus taxes & fees.

STEP 3: Please acknowledge your agreement to this statement by initialing on the line below.

___ I understand that this scholarship is to assist me to attend the 22nd Annual TMS Conference, September 2016 Orlando, FL. I am responsible for my own transportation expenses to and from the conference, and for parking fees, room service charges, room video fees, and any damages.

STEP 4: If I am unable to attend for any reason, including last minute illness or mast cell symptoms, I will contact Rita Barlow, 1-413-537-3174, or by email at: jbar51@verizon.net AND will also call the hotel at 1-800-342-4109 to cancel reservations. I am responsible for any charges incurred due to late cancellation, and/or failure to cancel.

Signature: ___________________________________________ Date: ________

Return this form to: Rita Barlow, TMS, 163 Main Street, PO Box 284, Russell, MA 01071-0284 or by email (scanned and signed): Rita Barlow: jbar51@verizon.net
The Mastocytosis Society 2016 Initiatives
By Susan Jennings, PhD, and Valerie M. Slee, RN, BSN

The Mastocytosis Society, Inc. (TMS) continues to serve its members and potential members by upholding our mission of research, education, patient support and advocacy.

Research:
- **TMS Mast Cell Disorder Patient Survey:** The second set of results from the TMS Mast Cell Disorder Patient Survey (The Mastocytosis Society Survey on Mast Cell Disorders: Part 2-Clinical Experiences, Co-Morbidities, Diets, Families and Opinions) is currently being prepared for publication in a peer-reviewed journal.
- **ICD-10 Codes for Mast Cell Activation Syndromes and Mastocytosis:** Proposals to create medical diagnosis codes (International Classification of Diseases, Tenth Revision, Clinical Modification; ICD-10 CM) for Mast Cell Activation Syndromes and update codes for Mastocytosis were developed as collaborative projects between TMS and the American Academy of Allergy, Asthma and Immunology (AAAAI) Mast Cell Disorders Committee. Changes to the ICD-10 CM codes related to these proposals, if approved by the CDC, are anticipated to become effective October 2016. As of February 2016 there are no further updates on the status of these coding proposals.
- **Mast Cell Disorder Challenges Meetings:** Over the last few years, The Mastocytosis Society, Inc. (TMS) has been hosting small ancillary meetings during the annual gatherings of several physician specialty associations. We have started referring to these small discussion groups as Mast Cell Disorder Challenges meetings because the purpose has been to bring together specialist physicians, drug company representatives and members of the TMS Research Committee to identify the primary challenges facing the mast cell disorder community in the United States and to explore possible actions that would address those challenges. The five Challenges meetings we have hosted are listed below.
  - **2014 American Society of Hematology (ASH) Ancillary Meeting:** TMS attended the 2014 ASH Annual Meeting (December 2014) and hosted an ancillary mast cell disorder meeting, bringing together specialist hematologists, drug company representatives and TMS Research Committee members for a discussion on Challenges in Developing Novel Mast Cell Disorder Therapies, moderated by Srdan Verstovsek, MD. The group agreed to meet again during the following 2015 ASH Annual meeting, with Srdan Verstovsek, MD, and Jason Gotlib, MD, serving as meeting Co-Chairs.
  - **2015 AAAAI Ancillary Meeting:** TMS hosted a Primary Challenges for Mast Cell Disorder Treatment in the U.S. meeting during the 2015 AAAAI Annual Meeting, bringing together specialist allergists, drug company representatives and members of the TMS Research Committee, moderated by Dean Metcalfe, MD, and Cem Akin, MD, PhD.
  - **2015 AAAAI Ancillary Meeting:** TMS hosted a Primary Challenges for Mast Cell Disorder Treatment in the U.S. meeting during the 2015 AAAAI Annual Meeting, bringing together specialist allergists, drug company representatives and members of the TMS Research Committee, moderated by Dean Metcalfe, MD, and Cem Akin, MD, PhD.
  - **TMS Pre-ECNM Meeting:** Susan Jennings, PhD, Research Committee, Co-Chair, attended the October 2015 European Competence Network on Mastocytosis (ECNM) Annual Meeting...
in Munich, Germany. Immediately prior to this meeting, TMS hosted a gathering of US physicians attending the ECNM meeting to discuss the possible formation of a US Network for Mast Cell Disorders. The idea was met with enthusiasm and Cem Akin, MD, PhD, and Jason Gotlib, MD, agreed to Co-Chair a committee to move forward with this initiative.

2015 ASH Ancillary Meeting: TMS attended the 2015 ASH Annual Meeting in December and hosted our second ASH ancillary mast cell disorder meeting, bringing together specialist hematologists and drug company representatives for a discussion on Challenges in Developing Novel Mast Cell Disorder Therapies, moderated by Srdan Verstovsek, MD (Dr. Gotlib had planned to co-moderate with Dr. Verstovsek, but had a conflicting meeting; he was able to attend for the end of discussions).

2016 AAAAI Ancillary Meeting: During the March 2016 AAAAI Annual Meeting, TMS hosted another Challenges meeting (Conquering Challenges in Mast Cell Disorder Therapy Development and Patient Care), moderated by Cem Akin, MD, PhD and Melody Carter, MD. A committee was assembled to work on the establishment of a US Network for Mast Cell Disorders.

US Network for Mast Cell Disorders: During the Mast Cell Disorder Challenges meetings hosted by TMS, the need for creating a US network of mast cell disorder centers and specialists was identified. TMS is committed to supporting activities that will lead to the formation of such a network under the leadership of Cem Akin, MD, PhD, and Jason Gotlib, MD, as Co-Chairs. The AAAAI Mast Cell Disorders Committee has also agreed to participate in this effort.

Patient Registry: TMS will defer work on a research-focused patient registry until a US Mast Cell Disorder Network is established. TMS supports the Mast Cell CONNECT Patient Registry, established by Blueprint Medicines, for patients with mastocytosis and its variants (www.mastcellconnect.org) as a first step towards comprehensive registries for mast cell disorder patients.

Grants:
2015 TMS Grant: $10,000 was awarded to Celalettin Ustun, MD, Division of Hematology, Oncology and Transplantation, Department of Medicine, University of Minnesota, for his proposal to study Mastocytosis in Acute Myelogenous leukemia (AML) with Core Binding Factors (CBF).

Patient Support and Advocacy:
- Patient Care Coordination is offered by three registered nurses Monday through Friday.
  - Provide assistance with applying for disability
  - Work with insurance companies to get coverage for patients with mast cell disorders
  - Work directly with patient’s physicians who have specific questions about care and treatment
  - Answer patients’ questions by phone, email and on Facebook

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Initiatives

...continued from page 39

• Offer support groups all over the US and endorse liaisons with support groups all over the world
• Patient conference held annually in early Fall with physician presentations, panel discussions, workshops, support groups, interactive sessions and casual time to mingle with patients, caregivers and physicians

Education:
• Continued presence at medical conferences to educate physicians: AAAAI, ACAAI, ASH, AAP
• Planning to add a dermatology conference pending a donor grant for this effort
• All essential information now offered on an easy to carry flash drive, including article reference list
• Educational materials updated regularly with Research Committee members

Political Advocacy:
• Teamwork has resulted in us getting closer to ketotifen being more readily available in the US
• Worked with RDLA, NORD, Global Genes and the Foundation Alliance on issues critical for patients with mast cell and other rare disorders

Communication/Media Relations:
• New website under construction with web design firm, Ministers of Design, based in Washington, DC
• New media packet in development for anyone wishing to write an article about mast cell diseases
• In preliminary discussions for a global support network with other support groups around the world
• Discussing possible international Mast Cell Disorder Day with Linda McMullan from Sweden

Pediatrics:
• $35,000 available for a pediatric grant, thanks to the Catalano family and Wyatt Warrior’s walk
• New web page for children in development

Fundraising Goals:
• For TMS Conferences
• For Research Grants, such as the joint AAAAI grant and the TMS grants we fund alone
• In anticipation of establishing the future US Network for Mast Cell Disorders

Thank you for Giving!

In order for TMS to continue its mission of education, advocacy and research we need your help. We would not be able to fulfill our mission without your generous support. Please consider making a tax deductible donation. We have created a new donation page on our website, please check it out… www.TMSforacure.org/donatenow

Ways you can give without ever writing a check!
Please go to one of these websites and TMS is a registered non profit!
smile.amazon.com • iGive.com
**Membership Application Angel Fund Waiver Form**

**Applicant Information (please type or print):**

Name: ________________________________ Child Member’s Name: ________________________________

Address: ____________________________________________________________________________

City: ___________________________ State: _______ Zip: _______ Country: ________________

Phone: __________________________    E-Mail: _______________________________________

Membership Type:   New _____ Renewal _______

**ANGEL FUND WAIVERS**

Patients who are unable to pay dues at this time can have their dues waived through the “Angel Fund Program”. This program was established to assist Patients with a Mast Cell Disorder to pay their dues. If you would like for your dues to be paid through the “Angel Program” due to financial hardship, please sign the statement below or you may send a letter requesting an Angel Fund Waiver (to the address above) or an email to: membership@tmsforacure.org

**NON-MEMBER ANGEL FUND WAIVERS**

Those who are interested in learning more about the disease who are not patients but would like their membership fee waived because of financial difficulties may send a letter to the Board of Directors (to the address above) or an email to: tmsbod@tmsforacure.org requesting a waiver which may be approved through another fund.

Relative _____ Spouse _____ Caregiver _____ Friend _______

Membership Type:   New _____ Renewal _______

Preferred Chronicle distribution method: E-mail _____ U.S. Mail _____ International Mail _____

I ________________________________ have a financial need and request a TMS membership through the Angel Fund.
There are many benefits of membership:

- **Four times a year members receive** The Mastocytosis Chronicles, an in-depth newsletter containing information such as: a message from the Chair, committee reports, insight to the latest research, news from the international mast cell disease community, updates from regional support groups, board meeting minutes, budget reports, as well as articles to nurture the body, mind, and soul.

- **Members receive a discounted registration to the annual TMS conference.** The annual conference offers programs and information for patients, caregivers, and parents of children with mast cell disorders. It also offers an informal forum for mastocytosis experts to meet and share ideas. Members with a financial need can apply for scholarships to assist in covering expenses associated with attending the conference.

- **Members benefit from the close alliance with each other** as they work together with mast cell researchers, caregivers, and other patients in the search for a cure for all mast cell disorders.

After a year of membership, active members are able to run for volunteer positions on the Board of Directors. All members are encouraged to enrich their experience by volunteering their talents in support of the TMS mission.

The Mastocytosis Society mission is to support all mast cell disorder patients regardless of specific diagnosis and whether or not they are TMS members. In the event that the fee poses a financial hardship, members may request to have the dues waived through the Angel Fund. If you have any questions on membership, contact: membership@tmsforacure.org.

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**Do You Feel Like an Angel? Are You in Need of an Angel?**

Throughout the year you can donate to The Mastocytosis Society's “Angel Fund Program” which is designed to help members and families that are in need cover their annual dues.

Angel Fund Waivers are completely confidential and recipients are only told their annual dues have been paid by an anonymous donor. Every $35 donation pays the dues for a new member!

You can donate at any time using a Credit Card, Paypal through our website (http://www.tmsforacure.org/donate.php), or by writing a check to: TMS, P.O. Box 191752 Atlanta, GA 31119, and designating an Angel Fund donation.

In addition, if you cannot pay dues, or know someone who cannot, please forward this information to them. TMS is committed to patient advocacy and this is one of many ways in which we can help each other through fostering community and patient education. You will find a reminder of the Angel Fund Program on every Membership application and Membership Renewal Form.
Support Group Contacts

United States

ARIZONA
Phoenix Rachael Nathan Sean-Michael Gettys
phoenixAZsupport@tmsforacure.org

CALIFORNIA
Northern California Michelle Lamanna
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Kathy Tomasic COSDMasto@gmail.com
sandiegosupport@tmsforacure.org
San Francisco
Cay or Ginny
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sandiegosupport@tmsforacure.org

SOUTHERN CALIFORNIA
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beggiato@aol.com

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mastocitosebrasil@gmail.com

CANADA
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306-789-9800

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e.V. Andrea Köenig M.A.-Chairwoman Marshallstraße
114 89231 Neu-Ulm, Germany
a.koenig@mastozytose.com
www.mastozytose.com www.mastocytosis.eu

UNITED KINGDOM
Dawn Brogden, Co-Chair
dawn@ukmasto.org
Jess Hobart, Co-Chair
jess@ukmasto.org
You can change the life of someone else with a mast cell illness! Spend a few minutes or hours each month helping The Mastocytosis Society research, educate, and advocate. Below is a current list of roles available within TMS. ALL VOLUNTEER ROLES require an application and interview to ensure the best volunteer placement possible.

**Nurse Line**
- Answer medical questions for patients and caregivers online and by phone
- Reports to: Valerie Slee
- Hours per week: on call as agreed upon
- Experience necessary: medical background necessary
- Skills necessary: communication skills, computer skills

**Chronicles Writer**
- Write feature stories, interview patients for stories
- Reports to: Sandy Johnson
- Hours per week: 1-2
- Experience necessary: writing background
- Skills necessary: Microsoft Word, computer skills

**Can you use me?**
You likely have talents and skills you could lend to the cause of research, education, support or advocacy. We need all types of people to come alongside the organization. Are you a leader, a nurse, an educator? Do you have administrative, financial, advocacy skills? These skills and many more could benefit the work of TMS.

**What’s the commitment?**
Volunteering makes an amazing impact when it’s done well! The idea of helping appeals to many people, but the realities of actually spending your free time to reliably get a task done is a bit more difficult. Below are a few things that we expect of new and interested volunteers:
- Demonstrated interest in the work of TMS
- Willingness to serve — commitment
- Ability to serve — time, support
- Something of value to contribute — knowledge and skill
- Professional reputation upheld — ethical and cooperative
- Reliability — will assume necessary responsibilities

Each volunteer role will require a different type of commitment. Most roles are flexible and if you plan ahead, accounting for days you may feel unable to volunteer, can be filled by anyone qualified.

If you see a role you’d like to participate in, please send us an application (found on the TMS website)! You can scan in your application and email it to volunteer@tmsforacure.org or you can write an email to that same address, answering all the questions on the application. If you’re qualified to help in an area not listed, please fill out the volunteer application and let us know how you’d like to contribute!

Volunteering Makes All the Difference!
Apply for a volunteer opportunity today
Meet Stacy Sheldon

New Pediatric Chair

As the mother of three boys, my family’s experience with Mastocytosis began over six years ago when my youngest son Caleb was diagnosed at 10 months of age with Pediatric Mastocytosis. Following his diagnosis, it was then discovered that I have Mast Cell Activation Disorder. The past few years have been quite a learning experience, and I am grateful for the information and support provided by TMS as my family learned to navigate this new world.

From 2011 to 2014, I served Mastokids in various roles, including Grant Committee Member, Board of Director, Treasurer, and President. In these positions, I worked with TMS to fund grants for Mastocytosis research. I have also been involved with the New England Support Group and local fundraisers. My family formed the group “Caleb’s Hope” for Erica’s Walk for a Cure in 2011. In 2012, I, along with my husband Steve, my parents and other family members, organized the fundraiser “Caleb’s Hope - A Night of Hope for Mastocytosis” in Wakefield, MA in honor of my son Caleb. The funds raised were donated to TMS, Mastokids, and the Center for Mastocytosis Excellence at Brigham & Women’s Hospital in Boston.

I am very excited to be joining the TMS board as your Pediatric Chair. I look forward to giving back to the TMS community, and I hope to be able to provide the same support and encouragement to those families facing a mast cell disorder diagnosis that my family received.

Main Support Group

We are meeting the second Saturday of every month.

Midcoast Hospital
Community Room (next to the cafeteria)
123 Medical Center Dr
Brunswick, Maine 04011

Contact; Liz Holbrook
Elizabeth.holbrook@maine.edu

Or on facebook at:
https://m.facebook.com/Maine-Mast-Cell-Disease-Support-Group-1524454134516620/
TMS DVD ORDER FORM

Shipping information (please type or print clearly):

Name: ____________________________________________

Address: __________________________________________

City: ___________________________ State: ___________ Zip: ___________________________

Country: ___________ Phone: ___________ Email: ___________________________

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<tr>
<th>Description</th>
<th>Quantity</th>
<th>Price</th>
<th>Total</th>
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<td>2006 – 4 DVD set</td>
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<tr>
<td>Car Ribbon Awareness Magnet</td>
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Shipping Costs: If purchasing multiple items please note shipping can be combined. Magnets ordered with DVD purchase does not require additional shipping.

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<td>$6.00 USA (DVD sets)</td>
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<td>$1.00 USA (Magnets)</td>
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Total Cost $  

Payment method:

___ Check/money order

___ Pay Pal- if paying through paypal please email order form to: treasurer@tmsforacure.org

Please make check or money order payable to: The Mastocytosis Society and mail check and order form too: The Mastocytosis Society (TMS), PO Box 191752 Atlanta, GA 31119.
The Mastocytosis Society, Inc
PO Box 191752 Atlanta, GA 31119

Membership Form

Applicant Information (please type or print):

Name: ___________________________ Child Member’s Name: ________________________

Address: __________________________ __________________________ __________________________

City: ___________________________ State: _______ Zip: __________ Country: ____________

Phone: __________________________ E-Mail: __________________________

Member: _____ Relative _____ Spouse _____ Child _____ Caregiver _____ Friend _________

Membership Type: New ($35) ______ Renewal ($35) ______ Supporting Member ________

Supporting Members are listed in The Mastocytosis Chronicles and will receive a thank you gift.

Copper Member ($75) ______
Silver Member ($150) ______
Gold Member ($250) ______
Platinum Member ($500) ______
Titanium Member ($1000) ______

Would you like to double your annual dues to include a donation to the Angel Fund for
individuals with a mast cell disorder that are unable to pay the annual membership fee of $35
Yes ______ No ____________

Total amount to be paid: ____________ (i.e., $35 dues plus one (1) Angel Fund donation of $35 is $70 total)

Check enclosed ________ Money Order ____________ Paid Online ____________

Make check or money order payable to The Mastocytosis Society, and send to:
The Mastocytosis Society, c/o Treasurer P.O. Box 191752 Atlanta, GA 31119

ANGEL FUND WAIVERS
Patients who are unable to afford to pay dues at this time can have their dues waived through
the “Angel Fund Program”. This Program was established to assist Patients with a Mast Cell Disorder to
pay their dues. If you would like your dues paid through the “Angel Program” due to financial hard-
ship, please send a letter requesting an Angel Fund Waiver (to the address above) or an email
to membership@tmsforacure.org.

Those who are interested in learning more about the disease who are not patients but would
like their membership fee waived because of financial difficulties may send a letter to the
Board of Directors (to the address above) or an email to tmsbod@tmsforacure.org requesting a
waiver which may be approved through another fund.

Preferred Chronicle distribution method: E-mail _____ U.S. Mail _____ International Mail _____
Preferred method of information packet for NEW members: Flash drive _______ Printed _______
Visit the Mastocytosis Society website at www.tmsforacure.org

Become A Supporting Member
Supporting Members are listed in The Mastocytosis Chronicles and will receive a TMS travel mug.

- Copper Member ($75)
- Silver Member ($150)
- Gold Member ($250)
- Platinum Member ($500)
- Titanium Member ($1000)

THANKS FOR YOUR SUPPORT!

Unsure When Your Membership Expires?
Your membership renews one year from the date on the mailing label.
To renew your membership, send your name, mailing address, telephone number, email address and $35 to:

TMS Membership
P.O. Box 191752
Atlanta, GA 31119

or pay by PayPal at www.tmsforacure.org