How to Communicate Well About Having a Mast Cell Illness
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If you would like to write an article, or have an idea for the Chronicles, please contact us at chronicles@tmsforacure.org, and put “Article Submission” in the subject line. Please note this is not a guarantee for publication.

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We thank each of these doctors for their time, caring, and expertise.

TMS is a 2015 National Organization Member of the National Organization for Rare Disorders (NORD)

TMS is proud to be a Lay Organization member of The American Academy of Allergy Asthma and Immunology (AAAAI)
I threw up in my mouth a little bit last night. After ten o’clock at night, I found myself tasting my lunch immediately after I had lain down. It happens sometimes, because I am blessed to have fantastical-reflux (no that is not a medical term). The head of my bed is raised the obligatory six inches. I’m taking a ton of proton-pump inhibitors and other stomach meds. I have a world-class GI doctor. And it still happens that every day: I cannot quite ever clear my throat, I am never sure when I will loose my voice, I feel like acid is burning away at will, and I can get those moments of chunks trying to make their escape up my throat.

Oh, and I woke up flushing red this morning, skin burning like I was on fire. Throwing the covers off, I waited for the overhead fan to offer relief. But it wasn’t enough. I knew quickly that today I would be starting my day with Benedryl. Not the perfect morning pick-you-up, mind you. I much prefer waking to feel like I have solid strength for the day ahead. And then having my morning Diet Coke. No haters please.

It was in the middle of a meeting I was leading at work that the nausea hit. Then that all-too-familiar feeling of dread started to wash over me, and my body couldn’t decide if it was cold or hot. I held out as long as I could, looking for an opening in

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the meeting to go find yet another dose of Benedryl. Chewables are my preferred remedy. They seem to work most quickly for me. And back to the meeting I went, hoping the medicine would catch up to my misbehaving mast cells.

Tonight it’s been trouble breathing. Okay, okay, the short-of-breath thing actually started in the afternoon at the meeting. But it’s been plaguing me all day. It is one of the symptoms I hate the most. Not feeling like you can take in a good breath is very, very disconcerting. And it’s energy draining too. I’m supposed to stop and use my inhaler when this happens. But it doesn’t always help. Sometimes it lasts all night, waking me up every half hour. Let’s hope that’s not true tonight.

So now I feel all used up. In truth, I have only mentioned less than half of the physical problems I’ve had all day. And for the record, today has been a relatively good day! Today I didn’t need my heart medication (knock on wood). I was able to run an extra errand. And I had time to talk with my college-aged daughter on the phone.

What I didn’t do today was any chores. I didn’t cook or clean. (Well, I did feed the cats, if you can call that a chore.) I didn’t put gas in the car, or give rides to my children. I didn’t even eat dinner with the family tonight, which is odd for our family.

Because I successfully navigated my day...steering carefully around major mast cell attacks and saving energy to write, I am able to write this now. Oh wait, the temperature in the room is off. Hold on....

Okay, I’m back. Sweater on (for probably two minutes). Fan turned off (for probably ten minutes). I cannot veer too far off the perfect temperature, lest I seize up from the cold and get super painful. I wish someone would put me in a bubble.

It’s ALWAYS something with mast cells! Why am I telling you all about my day? Why go into the details of my mischievous mast cells? Isn’t this supposed to be an article about how to communicate well about having a mast cell illness?

Why? Because my story, your story, is exactly where to start. It’s how I am communicating with you.

Human beings communicate with others for several reasons. First, we communicate to connect relationally. We offer ourselves to others through words or actions, and we want relationship...a connection between two people that shows concern for each other. While you might not know me personally, my story might have sparked a connection with a few of you. I certainly hope it helps me connect better with my husband who will be lovingly forced to read this later tonight.

Second, we communicate our story to offer information. We want others to know and understand what we experience and what we know. How many times have you felt like people you’re talking with don’t understand your mast cell illness? And how could they, without proper information. (Or how can they truly understand without having experienced anaphylaxis or a mast cell reaction?)

We also communicate to persuade others. Sometimes we talk and act in order to get someone else to do something particular. Ah...this is where communication turns into desire and expectation. This is when we’re communicating with a desired outcome in mind.

And finally, we communicate because it’s the socially acceptable thing to do. We make small talk, we exchange pleasantries at the drug store or bank, and we talk to people who call or ring our doorbell. It’s the socially acceptable thing to do.
Depending on whom you talk with, researchers would likely list many other reasons for communicating, but these four will have to suffice for the purposes of this article.

In addition to understanding the types of communication, whenever you’re talking about communication, it’s important to clearly define what communication is and is not. Remember that communication is NOT saying something out loud (or writing it down). The act of communicating requires a message, a message channel (like talking or writing), a sender (who encodes the message) and a receiver (who decodes the message). Communication only occurs when someone sends a particular message through a particular channel to another person who deciphers what it means.

So back to my story. What did I communicate by relaying my mast cell day? Did I connect with you? Relay information? Persuade you to action? Or simply meet a social obligation? What was my message? And what importance did my story have to me and to you? Whew…there are a lot of questions on the table at the moment. No wonder communication is so tricky. And no wonder communication about a rare disease that is so freakishly indescribable seems so impossible at times.

I read stories on Facebook every day about how someone has had a terrible experience trying to communicate about this illness. Heck, I go to work, where I have good friends who try hard to keep me safe, and I still have trouble communicating with them about this darn disorder. Sometimes, I’m not even sure what I think about how my health is behaving and what I need to do to live life well. And despite all that, my soul is dying to connect (to communicate) about it. Yet, I’m tremendously afraid that people won’t “get it.”

“Disappointment is unmet expectations, and the more significant the expectations, the more significant the disappointment.”

Brene Brown writes in her book, Rising Strong (which I highly recommend), “Disappointment is unmet expectations, and the more significant the expectations, the more significant the disappointment.” The purpose of her book is to help each of us learn we can rise from failure and distress and learn to live a wholehearted life. But this section of the book, where she dives into the topic of expectations, hit me right where it hurts. My expectations for myself and for others can trip me up all the time!

Brown goes on to say, “The way to address this is to be up-front about our expectations by taking the time to reality-check what we’re expecting and why. Expectations often coast along under our radar, making themselves known only after they have bombed something we had high hopes for into rubble. I call these stealth expectations.”

Oooo. Stealth expectations. Sounds like an action movie or a who-done-it mystery. And if you put our stealth expectations (expectations of how others will understand or treat us in light of our illness), our hidden meanings (things we hope people pick up on, but we never explicitly say out loud) and our misdirection (our tendency to make light of or use communication avoidance tactics when dealing with very difficult symptoms)...if you put these together, you have one massive communication storm. No wonder we’re disappointed with the outcomes...despite our very best efforts.
One thing I know for sure is that I need to root out the stealth expectations I have about how people will react to my mast cell illness story. I need to learn what I want from people and why I want it. And then I need to do the hard work of making my stealth expectations clear.

Stop right there. Some of you are screaming inside right now, because you are thinking…but I know what I want! My ____ (insert appropriate relationship here) doesn’t give me what I need/want even when I communicate clearly. Yikes! This happens.

One thing I know for sure is that I need to root out the stealth expectations I have about how people will react to my mast cell illness story.

If, if, if you have done the hard work to make sure you understand your message, understand the right communication vehicle and what you’re expecting and why from your communication, people can still refuse your needs/wants. That’s a different problem entirely.

But I would venture to guess that most of us don’t reflect very often on what we want when we communicate our story. So, let me go first.

Readers, I want those of you with mast cell illness to know there are other people out there who “get it” when it comes to mast cell illness, and I want you to work hard to be clear on what you’re trying to achieve when you communicate about your illness (so you can reach your goals).

I also want those of who you care for or are in any form of relationship with someone who has a mast cell illness to realize it touches every single part of our day, even if we aren’t showing active symptoms, and I want you to help your loved one clarify what they need when they try to communicate with you about their illness. I secretly also want some of you to stop minimizing this illness. Oops, guess that’s not a secret anymore.

And husband, as you’re being forced to read this tonight, I want you to know you’re one of the good guys. I know you don’t always understand this illness, but you try. And I also want you to know that every time you do housework, it leaves me more energy to write things like this. But I digress.

My story ends tonight with a fiery face from touching a hot computer for too long, the overhead fan about to be turned back on and likely an extra round of meds before bed. And by that, I want to communicate: mast cell illness is just plain hard.
I Wonder

By Jenny Tasker

I wonder if today, I will look like I once did, not so long ago, youthful, happy, even a little beautiful, or will I be swollen, my skin dehydrated, covered in hives, or God forbid, in full blown anaphylaxis? I wonder.

I wonder if today, I will be having a delightful spa-like shower, or will I spend most of this day in my bathroom, not the best view of my lovely neighborhood, suffering from the apparent trigger I have unknowingly come in to contact with. I wonder.

I wonder if I will be able to sit on my patio today, listening to the beautiful birds, and breathe in this delicious gift of fresh air, or if I will be confined to my bed, unable to keep even sips of water down. I wonder.

I wonder if today, I will be able to go for a walk, or maybe a nice farmers market, regardless if my feet and legs swell, or will my sheer fear, continue preventing me from going any further than the confines of my home. I wonder.

I wonder if people know how it feels, to be able to be home every single day with my family, to listen and join in on their laughter, and share in their joys. Or do they just see a pitiful 44 year old woman stuck at home, on disability. I wonder.

I wonder if when people take the time to ask how I am, they realize the amazing light filled gift they are giving me, just by wishing me well. (Yes we ARE, that powerful) Or do they think that their mere words are not enough, or don’t matter? I wonder.

I wonder if others realize this beautiful gift we are given, to wake up and have our very breath, to be able to share your light with the world, one more time. Or do they slam off the alarm and curse the start of yet another day. I wonder.

I wonder if the day will come, when we learn to lead with love, without judgment or hate of things we don’t understand. Or will we continue to make the same past mistakes, for fear of having an opinion of our own? I wonder.
Letter From the Chair
From Valerie M. Slee, RN, BSN, Chair

Early Fall Greetings! I am feeling buoyant with the cooler fall air, and glad to be alive to greet another glorious autumn! TMS is so grateful to all those who came to help us make our 2015 Capital Support Conference a success in Washington, D.C. Our wonderful hosts, Patricia and Fabio Beggiato, treated us to an amazing experience in our nation's capital, and we all learned so much from each other, from the physicians from NIH/NIAID, Drs. Metcalfe, Milner and Carter, and also from Dr. Theo. We concentrated on patient support and interactive sessions, and received lots of positive feedback from our attendees. Next year we will be meeting in Orlando, FL in September!

The TMS Board and Committees plunged right back to work. Mishele Cunningham is finalizing the enormous task of organizing the fall medical conferences where we host a booth, and checked on the volunteers who committed to staff our booth to educate physicians.

Jim McKee, our Treasurer, continues to accept and document donations to our Virtual Walkathon, which runs until December 31, 2015, and also manages the donations to other fundraising activities, like the Barbara Gittleman’s walk in October and Wyatt Warrior’s Walk in November. Keeping track of this on top of membership fees is a huge job, and we are lucky to have such an honorable man doing it for TMS.

Patricia Beggiato and Kelli Foster continue their advocacy work in D.C., with Kelli pushing forward and making sure that she handed the newly appointed FDA Commissioner, Dr. Robert Califf, copies of TMS literature! We are so fortunate to have this dynamic duo working front and center in Washington, spreading awareness and advocacy about mast cell disorders to powerful politicians and policy makers! Patricia is also the liaison to our new Web Master, Russel Hirshon of Ministers of Design, and has spent numerous extra hours with him doing all the preliminary work to design a new logo, new website design, and begin the work on content. We look forward to launching a completely new designed web site with many new features later this year!

We were sad to say goodbye to another Board member. Liz Smith moved into a remote area of Idaho, and will no longer be able to continue as Membership Chair. She did a great job, and we will be looking for another compassionate and energetic volunteer to replace her!

Rita Barlow continues her work with support groups, and works towards her goal of having one in every state. She is looking for more volunteers to help her and Cheri Smith work in establishing these new groups. Some of the support groups are exploding in size!

Susi Jennings and Nancy Russell, Co-Chairs of The TMS Research Committee, are working hours upon hours to complete the last analyses of the TMS Survey, and to prepare a second paper for consideration for publication. This is tedious, exacting work, and we are so fortunate to have these two professionals willing to volunteer their time to do this for all of us. The article that resulted the first time in Journal of Allergy and Clinical Immunology: In Practice brought tremendous attention and recognition of mast cell disorders to allergists and immunologists around the world. We will be thrilled indeed if our second paper is accepted for publication.
and continues that important work.

Additionally, the Research Committee is busy working on several huge initiatives. The first is hosting a luncheon meeting of U.S. physicians attending the European Competence Network on Mastocytosis (ECNM) meeting, to discuss how we move forward with establishing a U.S. Competence Network on Mast Cell Disorders. We have the support of our allergists and hematologists on our Medical Advisory Board, and so now we have to start writing timelines and criteria for how to move forward with this enormous step. We hope to learn from the experiences of our esteemed physicians who established the European Competency Network on Mastocytosis. In addition, we are discussing ways to fund education of physician fellows to staff these future Centers of Excellence and Reference Centers.

We also are in the midst of planning our Challenges Luncheons for both the American Society of Hematology (ASH) meeting in December, and the American Academy of Allergy, Asthma and Immunology (AAAAI) Meeting in March. At these luncheons, we meet with mast cell physician researchers and industry partners and address critical initiatives that need a cohesive action plan. The past Challenges meetings were very successful and we look forward to hosting them again.

Because there has been much discussion among our members and potential members about the use of tyrosine kinase inhibitors in patients with mastocytosis and mast cell activation syndrome, we also hope to host a discussion about this topic, possibly at the ASH meeting. We believe that open discussion, and offering patient full disclosure about all possible and/or potential side effects of any treatment option, along with obtaining a signed consent before initiating chemotherapy, protects the patient and the physician.

We continue our quest into finding the best option for a patient registry, along with guidance from our physicians. We have looked at several options, but have not yet identified the best choice for TMS. We are in discussions with several experts in this field, and are learning so much about it. We recognize what a serious decision this is, and above all, feel a responsibility to ultimately protect patient confidentiality and the integrity of the body of the data collected, so we continue to move forward with utmost caution. Please know that in no way have we put this on the back burner, but rather, are proceeding with careful thought and deliberation.

I know that this is a very busy time of year for families with children getting back to school, and holidays already occurring for some of our members and potential members. Please remember our Virtual Walk-a-thon, which funds many of the initiatives I have discussed above. If you have not yet sent out letters to your family and friends, telling them about your disease and what you do, now would be a good time! They can go directly to www.tmsforacure.org and donate online!

Happy autumn, and may you and your families, friends and pets be safe, healthy, and full of joy.

Respectfully submitted,
Valerie M. Slee, TMS Chair
The 2015 TMS Capital Conference

A Recap of Our First Support-Focused Conference
By Mishele Cunningham, RN, PHN, BSN

The weather was warm as people from all over the country descended upon Washington, D.C. for the annual TMS meeting. Friday started off with registration being run by Jim and Betty McKee, and a full hot breakfast for all. Attendees mingled with board members, doctors, specialists, and made new friends as the conference got underway. Patricia and Fabio Beggiato, our local conference hosts, got the ball rolling with introductions and announcements. The first speaker of the day was Valerie Slee, RN, BSN, Chair of TMS, who gave a mast cell primer talk, which consisted of an overview of all mast cell diseases. Because we held the conference in the Washington, D.C area, we were fortunate to be able to invite several esteemed physicians from the National Institutes of Health/National Institutes of Allergic and Infectious Diseases (NIH/NIAID).

Dr. Josh Milner was the first on, and he spoke on “A Familial Connection Between Mast Cell Disorders, EDS and Dysautonomia,” which was well received. He also touched on a new mast cell disorder called familial tryptasemia.

Next Dr. Dean Metcalfe, also from NIH/NIAID, spoke on “Indolent and Aggressive Forms of Mast Cell Disease.” Dr. Metcalfe reviewed diagnostic criteria, and current treatment modalities, and spoke on the different mutations that are seen within mast cell disease.

Dr. Melody Carter, from NIH/NIAID, spoke on “Pediatric Mast Cell Disease.” To round out the morning, Lauren Meyerson Long RN, BSN spoke to the group on how to navigate the National Institutes of Health. Her talk centered around how to become a patient of NIH, how to navigate the system, the different phases of clinical trials, and the studies currently taking patients (see NIH poster reprint in this issue). Friday morning ended with a panel discussion with all the speakers answering questions from the audience.

After lunch Dr. Theoharidis spoke to the attendees about “Neurocognitive Manifestations in Mast Cell Disorders.” Then we had another question and answer session with Dr. Theo.

Next up were two breakout sessions, one on how to get your physician to listen to you, presented by Valerie Slee, and one on the endless cycle of caregiving, presented by Patricia Beggiato. Both sessions transitioned nicely into the support group sessions.

TMS has learned over the years that the support group sessions led by Rita Barlow (patients) and Patricia Beggiato (caregivers) are one of the highlights of the conference for many patients. We have
also learned that patients really speak up when there are no caregivers in the room. The reverse is also true: caregivers can feel free to voice their frustrations and exhaustion in a room full of other caregivers, where no patients are present. So like previous years, all caregivers were asked to leave the patient’s room, and Rita led us in support discussions. It is always amazing to see how patients open up, and bring real concerns to the forefront. This year we were blessed with several new patients who happened to be specialists in the field of nutrition and psychology! This made for a lively discussion on everything from diet, to depression.

A casual meet-and-greet was planned for Friday evening on the rooftop patio. Everyone enjoyed the live music, and conversation, and fun was had by all. To say this was priceless is an understatement. Mast cell disease patients often feel isolated and alone. This time to gather, chat and have fun is always one of the highlights of the TMS annual meeting.

Saturday opened with a hot breakfast and the TMS annual member meeting. Each board member presented their annual report, and the TMS initiatives for the upcoming year were discussed. Dr. Susan Jennings, Co-Chair of the TMS Research Committee, then gave a full report on “Research Committee Future Options.” She discussed current research that TMS continued on page 14
The 2015 TMS Capital Conference

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has funded, talked about the survey that TMS did years ago, and the publication information that came from the data.

Next up we had an open question and answer session with a patient and caregiver panel. Led by Rita Barlow, the attendees were able to ask questions and get answers. After a short break, Valerie Slee and Mishele Cunningham led a workshop on “Anaphylaxis: Ask the Nurses What to Do.” This included a live epi-pen demonstration, proper emergency protocols, and a question and answer session on anaphylaxis.

The group was then split up and we had two workshops, one ran by Earlene Morgan, a local disability attorney, and one ran by John Staples on biofeedback for symptom relief. Both sessions were well attended, with a few of us falling asleep in the back of the room during the biofeedback! The session was so effective that we were so relaxed, we couldn’t help ourselves.

Just prior to lunch we had our annual silent auction and raffle. Volunteers Nicole and Reed Rogne spearheaded this endeavor, as they did last year, and it’s so fun to see all the items that people donate. Raffle tickets are sold throughout the conference, and silent auction items are up for open bidding. It was fun to see everyone’s excitement when they won a raffle item, or won the bid on an auction item. This years auction/raffle raised $1749.00 for TMS.

After lunch we started the afternoon sessions with Tiffany Blackden speaking on “Nutrition and Mast Cell Disorders.” This included time for question and answers and was very well received by all the attendees.

Dr. Theoharides took his afternoon and
met privately with any patients that wanted a consult. TMS is grateful to Dr. Theo for his expertise, and willingness to volunteer his time.

The next speaker was Mishele Cunningham who spoke on “Depression and Mast Cell Disease.” This topic is a common theme in mast cell disease, but often people are afraid to bring it up.

Our next session was with Daniele Polen, a yoga instructor who taught us how to do yoga from a sitting position. She went over ways to adapt yoga poses for each person’s ability. Once again in the back of the room a few of us may have become so relaxed that there was a little snoring heard.

Our final session was an informal open time to socialize and mingle. There were lots of hugs and a few tears of goodbye. Many attendees stuck around and joined the Board of Directors and remaining physicians at The Darlington House Restaurant for our annual appreciation dinner. The restaurant owned by the Beggiato family welcomed us with open arms. Their chef catered to our dietary needs, and the staff was exemplary.

This conference was more focused on support and practical advice for mast cell disease patients. About half the attendees had never been to a conference before, and the feedback was excellent. On behalf of the TMS Board of Directors, thank you everyone for your support. Whether you attended this year’s conference, or a conference in the past, we appreciate each and every one of you. There is nothing like meeting a mast cell patient and making life long friends. We hope to see you next year in September 2016 in Orlando, Florida!
1. I believe you.
People with mast cell illness may have been to numerous doctors or professionals looking for help. And many patients have been told they are crazy, drug seeking or “just fine.” Your affirmation of a patient’s explanation makes a huge difference, even though the signs and symptoms of mast cell disease may seem illogical or even improbable.

2. I want to understand.
We all want to be understood. When you take the time to listen to how a mast cell patient feels about their body, their limitations and their quality of life, you give them a gift. Take the time to really try to put yourself in their shoes.

3. I want to help.
Ask how you can be of help. Every patient’s needs are unique. Some need help with medications or activities of daily living. Some might need help with travel or shopping. Some might just need a friend who doesn’t disappear when symptoms are significant.

4. Let’s do something fun together.
Mast cell patients need friends. Many people with this illness have lost good friends who cannot understand or put up with the unpredictable nature of this illness. When you ask someone to do something fun…within their limitations…you give them a gift that will last a long time!

5. I support you unconditionally.
No matter how much or how little someone is impacted by mast cell illness, they want to know they have people in their lives who will fight the illness with them, not fight them. Support can be offered in many ways, but it’s the heart of caring that counts the most.

6. I hate this too.
While non-patients might not experience the symptoms of mast cell disease, they can experience the effects of the illness on family, friendship and their loved one. It’s okay and even helpful to let mast cell patients know that you don’t like the illness that keeps them down!

7. I am with you.
Mast cell patients can often feel alone. It is immeasurably valuable to know that someone will be there when the days are especially hard. Sometimes the gift of your presence is the best gift you could offer.
Is Research Driven Care a Good Option for Your Patient?

Lauren Meyerson Long RN BSN, Robin Etch RN BSN

Clinical trials are paramount in developing better understanding of a condition as well as identifying new treatments and medications. The Laboratory of Allergic Diseases (LAD) of the National Institutes of Allergy and Infectious Disease (NIAID) at the NIH conducts and supports clinical research related to allergic diseases. Referring your patient to the NIH is the first step in this collaborative effort.

Accessing Clinical Research Trials at the NIH:
Patients may be referred by a local health care provider or by self-referral.
- Office of Patient Recruitment
- ClinicalTrials.gov
- Clinicalcenter.nih.gov
- ResearchMatch.org

Patients must meet specific eligibility criteria for a study that is currently open to enrollment. Patients are screened carefully prior to scheduling an appointment.

Nurses play an important role in educating and supporting patients who investigate and subsequently participate in clinical research trials.

An NIH Research Nurse Specialist can help determine what medical records should be forwarded for LAD review and advise if a patient might be eligible for a clinical trial.

Types of Clinical Trials Currently Underway:
- Diagnostic Trials:
  Determine better tests or procedures for diagnosing a particular disease or condition.

- Natural History Studies:
  Provide valuable information about how disease and health progress.

- Treatment Trials:
  Test new treatments, new combinations of drugs, or new approaches.

Phases of Clinical Trials Currently Underway:
- Phase II Trials:
  An experimental drug or treatment is administered to determine its effectiveness and to further evaluate its safety.

- Phase III Trials:
  An experimental drug or treatment is administered to confirm its effectiveness, monitor side effects, compare it with standard or equivalent treatments.

- Phase IV Trials:
  After a drug is licensed and approved by the FDA researchers track its safety, seeking more information about its risks, benefits, and optimal use.

Connecting Your Patient to Research Driven Clinical Care at the NIH:

Current Studies at the Laboratory of Allergic Diseases:

Genetics and Pathogenesis of Allergy Section:
- Immune Disorders related to Allergies
- Atopic Dermatitis

Molecular Sign Transduction Section:
- Systemic Capillary Leak Syndrome

Food Allergies
Normal Volunteer Studies

NIH Working with You:
Participating in a research protocol may allow your patient the opportunity to try novel approaches to disease management. The NIH research team works closely with the local care providers for continuity upon your patient’s return home. The NIH team can offer recommendations and suggestions on how to manage unique disorders.

Ongoing communications between local care providers and the NIH Team may enhance clinical options available for your patient.

Resources Available for Your Patient:

There are several resources in place to assist patients who must travel long distances and who may also require lodging in order to participate in NIH studies. Patients are not billed for inpatient stays, clinic appointments, procedures or medications while at the NIH Clinical Center. Once enrolled on a study, patients who live more than 50 miles from the NIH campus may be eligible for government paid travel and lodging. On a case-by-case basis, a financial needs assessment through the NIH Social Work Department can identify patients who may need additional financial support for the first NIH visit.

The Edmond K. Safra Family Lodge and The Children’s Inn are lodging options on the NIH campus specifically designed for outpatients and their families. Accommodations at either of these locations are funded by the federal government.
How to Talk to Your Physician and Be Heard!
By Valerie M. Slee, RN, BSN, TMS Chair, Patient Referral Coordinator

You have been waiting for this appointment for months, and you are anxious to get there and have all of your questions answered. You wonder if you will like this physician, if you will “hit it off” with him or her, and if you will finally find someone who understands the complexities of mast cell disorders. You wonder, how can I best prepare for this appointment so that I make the most of it? Even if this is a return visit, preparing can help you make the most of it!

Before the day even arrives, you need to begin preparations. Type, save and print a sheet with your name, address, phone number, email, all current diagnoses and all current allergies. Next to each allergy, state what happens to you if you take the drug or food (i.e. penicillin- anaphylaxis; amlodipine- hives). Keep this and other lists in your computer and update regularly. Before each appointment, check to make sure all information is up to date.

On another sheet, list all of your medications by indications. The template for this can be found in the TMS ER Protocol: http://www.tmsforacure.org/documents/ER_Protocol.pdf (pages 4-7). You can print this out and fill it in. This will help the physician see and understand what medications you are currently taking, and why you are taking them.

On a third sheet, list all of your physicians, starting with your primary care physician, and specialists, including their addresses, phone numbers, and emails if you have them. This will be extremely useful so that the physicians can communicate with each other by sending notes about your visit to other specialists on the list per your request.

The fourth list is for your personal use during the appointment. Make a list of your chief concern for this visit, and list specific questions you have. Post this list on your refrigerator, and add to it as you think of things you would like to ask in the days leading up to the visit.

Good work! Now, see if you can get a spouse, caregiver, or good friend to go with you. A second set of ears is always helpful. Ask that person to take notes so you can concentrate on listening to the doctor.

You are on your way! The big day has arrived. You have done your prep work, and you want to be heard. However, the reality is that patients are allowed to finish their opening statements less than 23% of the time according to a study in the Annals of Internal Medicine. So how can you be heard once you arrive?

First of all, understand that you have 15 minutes or less for this entire appointment. Seriously! Most physicians are expected to see at least one, if not two, patients every 15 minutes. This puts a tremendous amount of pressure on even the best,
most compassionate physician. Start out by greeting your physician warmly, and connecting with him/her on a human level in some way: “Wow, thank you for seeing me. I can see how busy you are today!”

This compassion expressed for your physician may make your physician more likely to feel compassion for you! Now that the greeting is over, get down to business. The clock is ticking...

1. State the reason for your visit, and that you have a list of specific questions that you need to have answered. This allows you to set the pace for the visit.
2. When giving your history, be concise and to the point. Not, “I started out as a preemie”, but instead,” I have MCAS, and was diagnosed at age 34. I am also a diabetic on insulin and have POTS. If this is a repeat visit, state the reason for it: “I have been having pain in my abdomen over the past three months.”
3. When the physician asks you a question, stop paying attention to your list, Make eye contact and answer the doctor! You want him or her to know you are engaged in the visit!

One of the most difficult parts of being a patient with a chronic illness is trying to be objective while describing the misery you experience on a daily basis. In a physician visit, it makes a big difference if you can describe your symptoms objectively. Physicians turn off if patients repeatedly describe pain, for example, as “it was the most excruciating pain I have ever had, it was like knives going through my back”.

Much better: I had pain in my upper right abdomen over the last month and it radiates to here (point to spot). I feel nauseated with the pain. It varies from 6-8 on the pain scale of 10. One night it woke me up and was 9 out of 10.”

continued on page 20

**There’s an App for that!**

**Find Apps That Help You Cope With Chronic Illness**

Want to track your doctor visits and questions for your physicians? There’s an app for that. Here are two we found effective. (As always, please consult your physician with medical questions, problems or before making significant health-related changes.)

**Medisafe**

The leading medications manager on the app store, Medisafe helps you manage your medications, pills, refills, measurements and doctor appointments. It is designed to help you take your medications on time, help with refill reminders and provides family data. In addition, you can share your data with other users and caretakers can be notified if you don’t check in that you took your medication, so they can remind you if necessary. It can also be used to manage health conditions, keeping track of your doctors, your doctor visits and your health diary.

**My Medical**

This app is a comprehensive medical record-keeping app. You can use it for the entire family, keeping all your important medical information in one place. With too many features to list, along with health records, this app has areas for emergency contacts, insurance information, doctors’ contact info and other data. It will also help you plan for those upcoming doctor appointments.

Have a favorite app? Email us at editor@tmsforacure.org, and we may share it in a future edition of The Chronicles!
Sometimes, it seems like the physician may not be asking the right questions, or does not seem to be understanding your problem. Concisely expand your narrative to redirect him or her: “The pain is right here, and it gets worse 1-2 hours after eating, when it becomes 8 on the pain scale. It had woken me up at night. What could this be?”

If you are lost, and do not understand what the physician is saying, say, “Wait please. I am lost. Please slow down and explain again.” It is important to recognize that this is no reflection of how smart you are or how good or bad of a teacher the physician is, but rather, is almost always a result of time stressors on the physician. However, you are paying for this visit, so respectfully ask for appropriate care.

If the doctor asks you a questions that seems bizarre, unrelated to your illness, or just plain confusing to you, simply ask, “Why is that important, Dr._______?” Include the physician’s name so he or she knows you are being respectful but are simply confused by the questions.

If the physician starts to signal the appointment is over, and you have not had all of your questions answered, say, “Wait--I still have a few important questions here. The first one is...” And immediately ask the first one. Do not dawdle. Do not waste time looking for permission to proceed. Obviously the physician is feeling pressure to move on to the next patient, so be respectful of that and ask your questions so you can both be done. If the physician states that he/she is out of time, ask:

1. How can I best contact you to get the rest of my questions from this appointment answered?
2. How do I contact you in an emergency?
3. Do you correspond with patients by email?
4. Do you do phone appointments?
5. When do you recommend a follow-up appointment?

In summary, In order to be heard at your next appointment with a physician, do your work ahead of time. Prepare all the information discussed in this article, and print copies for the physician to keep, saving time for the staff. Know why you are going to this appointment, what you hope to accomplish specifically with this visit, and have your list of questions ready. Be respectful of the tremendous pressure your physician is under in terms of time and work duties, while keeping in mind that you have the right to have your medical needs met and your questions answered. Make eye contact with your physician, be compassionate to your physician and understanding of the stressors affecting him/her, and always be an advocate for yourself! Follow up with your physician if you have any difficulty following any instructions given to you during your appointment. Be prepared. Be informed. And be strong!

References


Thank you to Susan V. Jennings, Ph.D, and Nancy Russell, Dr. PH, Co-Chairs of the TMS Research Committee, for reviewing this article.
Facebook Friends…
on Communicating Mast Cell Illness

We asked…you answered!

How do you communicate to others what it’s like to have a mast cell illness? We posed this question to our Facebook community. And we’ve chosen the top twenty answers – some creative, some poignant and some just plain hard! Hopefully these answers provide you with some ideas about how you can talk to others about your illness. Or at least make you laugh.

Or, if you’re a caregiver or a loved-one of someone with a mast cell illness, read on. These answers just begin to describe the constant difficulty of living with mast cell illness. Hopefully they can help you see your loved one’s reality in a new light. But one note of caution: please don’t get caught in the comparison trap. It’s not at all helpful to patients to hear their loved ones compare their suffering to others. Everyone’s experience is similar but not at all the same.

I tell people that mast cells are like naughty teenagers who will throw a party at any time, for no reason at all!

Julia

Having MCAS causes my body to misinterpret normal things, like foods, heat, stress, or vibrations, and react to them as if they were allergens, resulting in hives, flushing, shortness of breath, fainting and sometimes anaphylaxis. It also causes chronic daily pain and fatigue.

Having a mast cell disorder is like walking a tightrope. You hope for a nonreactive day, but one small trigger can result in losing your balance and plunging into oblivion. The food you ate with no problem yesterday, stress from daily life, or the perfume a passerby is wearing can all send you into a tailspin. Gone are the days of carefree adventure. You always need to be close to a bathroom, have medications to treat reactions, and carry a mask in case of triggering scents. Having an invisible illness takes all of your strength.

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Mastocytosis is like having a bit of diabetes, some IBS, with a dash of dementia. Add a splash of congestive heart failure, a dose of asthma, a hint of eczema, with just a side of arthritis. As I tell people this, their eyes get big, and they nod their head finally beginning to “get it.”

Michelle

Its ugly, embarrassing, gross, unpredictable, excruciating, disrupting, debilitating, and life altering.

Lori

I generally say that having Mastocytosis is like having the flu every day. Some days with the flu, you want to die, you hurt all over, you have a terrible headache, you could be vomiting and doubled over from the pain, and you don’t want to, or can’t get out of bed. Then on days when the flu is not quite as bad, you might just be dizzy and don’t want to get too far from the bathroom, but you can get a few things done. For me it is different from one day to the next.

Julie

I tell people that my body is attacking itself. Imagine a symptom, and I probably have experienced it. I have to take lots of medicine every day just to...
stay alive and even then anaphylaxis comes frequently and is life threatening. 

*Patricia*

It feels like a high fever with a sunburn while coming down with stomach flu. Itchy, achy and having asthma. Anxiety with every bite of food, with enjoying a sunny day or with getting an accidental whiff of your daughters perfume as she hugs you goodbye. Fear engulfs you as you pray you don’t die. 

*Genia*

Ever been around an untrained bird dog? My immune system overreacts to everything! 

*Amy*

Having MCAS is like being linked to a voodoo doll in the hands of a sadist. Today, a pin in my shoulder, tomorrow my knee, Thursday my ankles...I just never know what’s coming. Pins in my head, my eyes, my nose, my bones, my stomach, my throat...always changing, but ever present. These pins are invisible to those around me. Those who claim to care, see no reason for my pain. “It’s in her head they say,” or they offer advice devoid of empathy. How do I explain MCAS? To those who I know care to listen, I say it is like something trying to kill you, by every means possible, from the inside out. And it takes all my strength, everyday, to get up, dress up, and show up; but I am determined to do so. And I will smile at the hand of the sadist, and yell, “Do your worst, I’ve seen bigger needles in the ER!”

*Shannon*

Imagine having the flu, only 1,000 times worse, and it never goes away. And that’s only a tiny portion. You’re in constant fear of anaphylaxis, anxiety, so much to deal with. It takes a toll on you emotionally, because every decision you make is based on how you are reacting to the mast cells or will you react while out? Then it’s just not worth the risk, and you stay home all the time.

**Caregiver Queries**

It’s hard to know how to help sometimes. And when your well-meaning words aren’t quite right, patients can sometimes feel that caregivers don’t fully appreciate their unique issues. And caregivers can find themselves frustrated with those who are experiencing pain or illness for a number of reasons.

So, what questions can you ask your loved one or friend who has a mast cell disorder that will help you better understand or care for them? Here are a few to get you started:

- Tell me what a good day is like for you.
- Tell me what a bad day is like for you.
- What can I do to help on a good day?
- What can I do to help on a bad day?
- How do you want me to ask you about how you’re feeling?
- What if I notice you’re not feeling or looking quite right? What do you want me to do or say?
- When (or at what level of symptoms) do you want me to stop what I’m doing to care for you?
- When do you want me to simply work through your symptoms on your own?
- What things do others or I say or do that make you feel like your illness is being minimized?
- What do you need me to do (or what role do you need me to play) if you need to see a doctor or visit a hospital?

These are just a few questions to get you started! We hope they prompt some excellent conversations in your family or with your friends and co-workers.

Please remember as you are listening for answers that talking about mast cell illness can be very difficult, because many patients have been dismissed by physicians or loved ones because they look relatively healthy, and because this illness is episodic in nature. If you need to start with an apology for being dismissive, it could help heal and strengthen your relationship. Give it a shot. Then listen fully to what your loved one is trying to tell you about their illness and preferences.
Debi

It feels like having any one of an array of symptoms (58), at any given time, to any severity, from any trigger that you have either touched, or eaten, or smelled or worn. It’s constant work to keep yourself as close to stable as you can.

Linda

It feels like my body has betrayed me. I never know when I will react to something new. I may be fine with something today, and it try to kill me tomorrow. I feel like I’m constantly apologizing for inconveniencing others with my unpredictable reactions. In a way, it feels like I don’t even know myself anymore.

Marla

MCAD is like being allergic to different things on different days with no warning, including emotions. For me it sends a wave of prickly-feeling heat that consumes my body and then gets replaced with hives that don’t go away for hours or sometimes days.

Jennifer

When I’m in a flare, it’s like trying to wade through wet concrete, moving feels so heavy and slow and impossible. Thinking clearly is impossible, because it feels like all your perceptions are being filtered through static fuzz. You’re so exhausted, you don’t know where the energy is going to come from to take a shower or make a simple meal. You often give up on projects halfway through out of sheer frustration or exhaustion, or both.

Marissa

It’s like having fire ants perpetually stinging your skin and eyes while trying to stay upright on a violently rocking boat.

Donna

It’s very hard to explain any chronic disease that doesn’t fit into a neat little box, whether it be to a medical person, a friend or family member. The symptoms are so varied and random that it is hard for an “outsider” to comprehend, and when you try to explain, more often than not, you see their eyes start to glaze over. The only people who begin to get it are the ones who watch your suffering on a daily basis, and if you are lucky, they begin to ask questions, learn about the disease and become supportive. There’s nothing much worse than feeling like no one understands or cares when you are dealing with an unknown chronic condition that robs you of living a full life, because you never see a light at the end of the tunnel.

Carole

I tell them it’s like being allergic to everything and nothing, where you remove all the rules and add a bunch of WTH?

Yvonne

I just recently told friends after doctor appointments that I feel like Dorothy when she tells the Wizard of Oz, “Oh, I don’t think there’s anything in that black bag for me.” To those that are very close to me, I’ve told them I feel like some of my organs, bones and bone marrow have betrayed the rest of me.

Lynn

It’s the Twilight Zone of diseases. Can’t make this stuff up.

Jan
We have an important change that we are making, and we would to explain our reason for doing so to all members of TMS. A few years ago, discussion centered on changing the name of our organization to include Mast Cell Activation Syndrome. At the time, we took a membership vote, we sought advice from our physicians on our Medical Advisory Board, and it was felt that there was such brand name recognition already associated with The Mastocytosis Society, Inc. that we should not alter the name. Shortly after the decision to retain that name, the Board voted to add a tag line to our name that said Mastocytosis Mast Cell Activation Disorders. Since that time, we have added this tag line under our name, and have incorporated it into our bylaws. Our goal was to recognize and be all inclusive of patients with all forms of mast cell disorders.

Once again, science has changed, and we have learned even more about mast cell disorders. A new variant called autosomal dominant familial tryptasemia has emerged, and we heard Joshua Milner, MD, present on this at our TMS Capital Support Annual Conference in Washington, D.C. in August, 2015. There were patients and family members present in the conference room affected by this newly recognized entity. This brings up the possibility of even more variants of mast cell disorders being recognized. How do we accommodate all of them in our tag line?

We discussed this among ourselves, and sought counsel from some physicians from our Medical Advisory Board who also serve on the AAAAI Committee on Mast Cell Disorders, chaired by Melody Carter, MD. The consensus was to change the tag line to Mast Cell Disorders, to be inclusive of mastocytosis and all of its variants, mast cell activation syndromes, familial tryptasemia, and any other new variant or entity that may be identified. We are grateful to incorporate this new tag line to our new logo, unveiled in this issue of The Chronicles and on our website later this year, and to have the opportunity to include all patients with mast cell disorders in The Mastocytosis Society, Inc. If you have any questions, please email us at tmsbod@tmsforacure.org. Thank you.
I was diagnosed with Cutaneous Mastocytosis in 2011. My diagnosis was completely accidental. At the time, I was living in the Southwest, and hot springs were a big part of my downtime. After long soaks, I began to develop spots on my legs that looked similar to freckles or sun spots. My mom encouraged me to see a dermatologist and after a skin biopsy, I was diagnosed. I remember the dermatologist saying it was common and not to worry.

What I wasn’t prepared for was the overwhelming information I found online when I began to research this rare and not so common disease. Honestly, what I felt was very scared and very alone, and I couldn’t help but fear this would lead to something more severe. I have always been a nervous person and have struggled through bouts of depression, but what came after the diagnosis was something I had never known. I developed anxiety and panic attacks; surges of adrenaline that left me physically depleted.

I began to develop other symptoms that may have been minor annoyances for years but were now making a much bigger presence. My entire left arm became covered with permanent reddish brown lesions; I began flushing as well as struggling with bowel problems (either not being able to make a bowel movement or being plagued with diarrhea). My skin would itch at random as well as the appearance of an occasional hive.

Doctor’s visits became futile; while they focused on anxiety and depression, the mastocytosis often took a back seat. Rather than admit their unfamiliarity with the disease, most doctors simply said, “you seem fine.” I remember one dermatologist leaving the exam room to look up mastocytosis online.

I finally found a doctor who was familiar with the disease, and then I lost my insurance. My tryptase remains low, but symptoms remain constant.

One thing that was never made clear to me was the importance of an antihistamine to reduce my overall histamine load. I was under the assumption antihistamines were for those with severe itching or hives. I was also given samples of sodium cromolyn as well as learned about the possible benefits of quertecin. But nothing has been more helpful than connecting with The Mastocytosis Society, both as a resource for information and as a means to end the isolation.

Those of you with this diagnosis understand the hamster wheel of fright and uncertainty. My hope is to make new connections and friendships as well as expand my own understanding of the mastocytosis community.
Many people come in and out of your life. And when you have a chronic illness many more people seem to leave. I have never blamed my “friends” for deserting me. After all I was sick...still am, and always will be. While thinking about this over the past year, I came to realize that I was wrong, that maybe I should blame them. If those people were my “friends” they would have stuck by me, despite my depressed moods, medication side effects, and masto-rage moments. Those things don’t define me. My disease does not define me. I am more than my disease. However, I am thankful to my disease for bringing real friends into my life.

Angels: this is what I call my real friends, even the ones I have never met. Let me explain. Mast cell disease can be very isolating, even to the healthiest of us. We tend to not wander into the mall for fear of the perfume spraying ladies of Macy’s. We decline dinner invitations or celebration dinners due to not being able to eat the food provided or for fear of becoming sick or needing to spend the whole time in the bathroom. We sufferers, we hide, we make excuses, and then...we meet our angels.

You know, the people who suffer like you: the sufferers on Facebook, creeping into the wee hours of the night, because they can’t sleep. The volunteers of TMS who answer emails at 2:00 a.m. or take your phone calls and will sit on the phone with you for an hour. The friends you met at a support group meeting months ago who you can text or call any time for some cheering up. That person who you compared spots with at an annual meeting. Angels. They are all angels amongst us.

I have met many angel friends on my mast cell journey. People from all over the world, all socioeconomic backgrounds, different cultures, and beliefs. But the one thing that binds us together is our disease and a hope for a cure.

I encourage you, yeah you reading this, to reach out to some of those people you have met, and made friends with those who have a mast cell disease. Say hi, ask how they are doing, let them know how much their friendship means to you. Chat, catch up, and for just one conversation, don’t talk about your disease. Your disease does not define you. The angels we meet in life make sure of that.
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, PO Box 129, Hastings, NE 68902-0129, 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.

Are You A Member In Need Of An Angel Fund Membership?

Members 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 Members 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 send a letter requesting an Angel Fund Waiver (to the address above) or an email to membership@tmsforacure.org.
Fundraising Report
By Patricia Beggiato

Thank you to all of those who have hosted fundraisers, planned events and collected donations for The Mastocytosis Society! TMS is a non profit organization and fundraising is a crucial part of being able to fulfill our mission of research, education and advocacy.

There are 2 upcoming Runs/Walks benefiting TMS in Michigan and Northern California:
- Barbra Gitterman has raised thousands of dollars through the years and we are most grateful to her efforts! Her annual walk in memory of her daughter Sarah has helped so many TMS members by helping us to continue our mission! She will be hosting her walk this year on Sunday October 4, 2015 in Huntington Woods, MI.
- Walk for Wyatt will be hosting a 5K Run/Walk in Gilroy, CA on November 1, 2015. Please support and follow his story and website at MastoWyattWarrior.org. We are so grateful to Wyatt’s family and friends who are helping to raise awareness and funds for TMS!

In order for TMS to accomplish its many goals it is imperative that we increase ways to raise funds. I aim to accomplish this through applying for public and private grants.

We are also increasing awareness with other rare disease advocacy groups to ensure that mast cell patients have a seat at the table. And we encourage other members to raise their voice and become engaged with rare disease legislation that could affect them.

Medical Conference/ Education Report
By Mishele Cunningham RN, PHN, BSN

Educational Initiative #1: Attend Medical Conferences to Educate Medical Personnel
We attend the following conferences as exhibitors to educate doctors, nurses, and other medical professionals on all types of mast cell diseases:
- American Academy of Pediatrics (AAP)
- American College of Allergy, Asthma and Immunology (ACAAI)
- American Society of Hematology (ASH)
- American Academy of Allergy, Asthma and Immunology (AAAAI)

Educational Initiative #2: Educate Patients and Their Caregivers on Mast Cell Disease
TMS is contacted every day by mast cell patients from across the globe. Contact is via Facebook, email, phone calls, text messages, and sometimes through the patient’s doctor. A very dedicated group of volunteers answer these calls for help, and provide educational material, patient referral assistance, and medical information.

Educational Initiative #3: Work very closely with the Medical Advisory Board doctors to keep all of our written material up to date.
In conjunction with the doctors, and our research committee, we write our pamphlets, the special edition of the chronicles, and all other printed material.
Membership Report

By Elizabeth Hill

We have a strong membership base with a current count of 621 members. Member benefits include: quarterly newsletter, discounted registration at our annual TMS conference, priceless close alliances with fellow patients and caregivers, annual meetings open to all members, and the opportunity to contact our Board of Directors with your critical input...all for just $35 per year.

If you are unable to afford our membership dues, consider our “Angel Program.” If you would like to have your dues to be paid through the Angel Program due to financial hardship, please send the angel fund waiver form to membership@tmsforacure.org.

Every new member receives a new member packet containing our welcome letter, printed TMS brochures that are helpful in understanding your Mastocytosis/MCAD, an ER wallet card, the current issue of The Mastocytosis Chronicles, the current Special Edition of The Mastocytosis Chronicles, and our DVD: Mast Cell Activation Symptomatology. We also include a pediatric “Spot” card if the member is a child.

Your membership matters! Be a part of the search for a cure! Together we can make a difference!

Research Report

By Nancy C. Russell, Dr.P.H. & Susan Jennings, Ph.D., TMS Research Committee Co-Chairs

Valerie Slee, RN, BSN, Mishele Cunningham, RN, BSN, PHN, Celeste Finnerty, PhD, TMS Research Committee Members

2014 American Society of Hematology (ASH) Annual Meeting:

Dr. Jennings attended the December 2014 ASH Annual Meeting in San Francisco with other representatives of TMS.

2015 American Academy of Allergy Asthma and Immunology (AAAAI) Annual Meeting:

Drs. Russell and Jennings, along with Valerie Slee, RN, BSN, TMS Chair, joined other members of the TMS team at the 2015 AAAAI conference in Houston, TX, and attended a variety of medical and scientific presentations. Dr. Jennings also attended the AAAAI Mast Cell Disorders Committee and Lay Organization meetings with Valerie Slee, RN, BSN, TMS Chair.

2010 TMS Patient Survey Update at the AAAAI Annual Meeting:

Drs. Russell and Jennings and Valerie Slee, RN, BSN, presented a poster of the second set of results of the TMS 2010 online survey of mast cell disorder patients, Clinical Experiences, Co-Morbidities, Diets, Families and Opinions. These second results are also currently being prepared for submission to a peer-reviewed scientific journal.*

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Challenges in Treatment of Mast Cell Disorders in the U.S. (Focus Group Meetings):

Recently, TMS has tried a new approach to encourage productive discussions between mast cell disorder specialists, drug and biotechnology companies, and our patient organization by hosting focus group sessions during the annual meetings of two medical specialist societies (2014 ASH and 2015 AAAAI). These sessions were geared toward identifying challenges related to mast cell disorder treatment and involved efforts to brainstorm solutions for our primary challenges. During the 2014 ASH Annual Meeting, Srdan Verstovsek, MD, served as our discussion moderator. Dr. Verstovsek, along with Jason Gotlib, MD, have agreed to serve as Co-Chairs for the discussion during the upcoming 2015 ASH Annual Meeting. During the 2015 AAAAI Annual Meeting, the discussion was moderated by Dean Metcalfe, MD, and Cem Akin, MD, PhD. Drs. Russell and Jennings, Valerie Slee, and Mishele Cunningham participated in these meetings as representatives of TMS. Action items based on these discussions are currently being developed, with a primary goal of creating a US Competence Network for Mast Cell Disorders.

ICD-10-CM Codes for Mast Cell Activation Syndromes (MCAS) and Mastocytosis:

In 2013-14, TMS Research Committee members worked with the Mast Cell Disorders Committee of the AAAAI (including Drs. Arnold Kirshenbaum, Joseph Butterfield, Cem Akin, Mariana Castells and Catherine Weiler) to create proposals for new medical diagnostic (ICD-10-CM) codes for MCAS and revised codes for mastocytosis. These proposals were submitted jointly by TMS and the AAAAI to the Centers for Disease Control and Prevention (CDC) and were presented during the CDC Coordination and Maintenance Committee Meetings held March 19-20, 2014 (MCAS) and September 23-24, 2014 (mastocytosis). Changes to the ICD-10 CM codes that would relate to these proposals, if approved by the CDC, are expected to become effective October 2016.

TMS Research Grants (First Half of 2015):

- Jonathan Lyons, MD, National Institute of Allergy & Infectious Diseases/National Institutes of Health, was awarded the “2015 ARTrustTM/The Mastocytosis Society Research Award in Mastocytosis and/or Mast Cell Activation Syndrome” ($60,000 joint grant with the AAAAI) for his proposal, Convergence of Autosomal Dominant Familial Tryptasemia and Mast Cell Associated Disorders.

- Celalettin Ustun, MD, University of Minnesota, was awarded a TMS research grant ($10,000) for his proposal, Mastocytosis in Acute Myelogenous Leukemia (AML) with Core Binding Factors (CBF).

*First set of survey results has been previously published:
2. TMS Chronicles (Winter 2014)
Support Group Contacts

United States

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Chairwoman
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www.mastozytose.com
www.mastocytosis.eu
phone: Hannelore Laun: 0049 (0)6104 - 74281

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shawna.lechner@sasktel.net
support@mastocytosis.ca
306-789-9800

Rainer Wannemacher and Professor Raithel work together on behalf of MCAD/MCAS patients. Rainer Wannemacher works on behalf of MCAD/MCAS patients and has a group for these patients in Germany. Email: rwanne@gmx.net Professor Raithel, Gastroenterologist, at the University Hospital Erlangen, also works with MCAD/MCAS patients.

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.

Membership Chair – Immediate Opening
- Maintain membership database. Prepare and mail out new patient information packets. Communicate effectively and with compassion with all new and potential members of TMS via email, phone and postal mail. Relay new membership fees to treasurer if necessary. Work cooperatively with the Board to raise membership numbers via membership drives.
- Reports to: The TMS Board, Valerie Slee Chair
- Hours per week: 20-25 hours per week minimum
- Requirements: At least one year of TMS membership. Familiarity with TMS. A working and up-to-date personal computer, fax machine, scanner and reliable Internet access are critical. Access to a post office is also vital.

Extra information: The membership chair is a critical member of our team, and is often the first point of contact for new members. We need someone energetic and sensitive to the needs of the mast cell patient and caregiver community to help us with this very important job!

Secretary Board of Directors – Immediate Opening
- Set up and attend monthly TMS Board meetings and keep required notes of all meetings, including annual meeting minutes. Maintain all important documents. May volunteer on any TMS committee, and must uphold our TMS mission.
- Reports to: The TMS Board, Valerie Slee Chair
- Hours per month: Approximately 4
- Requirements: At least one year of TMS membership. Familiarity with TMS.
- Skills necessary: administrative skills, computer skills

Assistant Treasurer
- Assist with managing the finances for TMS
- Reports to: Jim McKee
- Hours per week: 3+
- Potential hours per week: 25 if working to replace current treasurer
- Experience necessary: bookkeeping, administration
- Skills necessary: Quickbooks (skilled), PCAnywhere (will train), FileMaker Pro (will train)

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

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

Volunteer Coordinator
- Help manage volunteer opportunities and place volunteers in appropriate roles
- Reports to: Sandy Johnson
- Hours per week: 1-3
- Experience necessary: volunteer or employee management
- Skills necessary: leadership background, computer skills

Grant Writer
- Locate and apply for various grants
- Reports to: Valerie Slee
- Hours per week: varies per project
- Experience necessary: grant writing, research or technical writing
- Skills necessary: computer skills, research skills

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!

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.
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

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UK Support Group Changes

Irene Wilson founder of the UK Mastocytosis Support Group since 2004 retired on 3rd October along with two of the group’s very first members: Roger Richmond who was Charity Coordinator and Elizabeth Richmond, Roger’s wife, who has Mastocytosis and was Group Secretary.

Irene was very pleased to accept the position of Honorary Chair of the UK Mastocytosis Support Group.

Irene said: “I was never able to find another person in the UK with Mastocytosis, having been diagnosed in 1980. It was thanks to the late Iris Dissinger, a good friend of mine from TMS, who put a mention in Chronicles for me way back at the beginning of 2004 looking for people in the UK to contact me with a view to forming a Mastocytosis Support Group. One by one people made contact and so our group was started. The fantastic help I received from TMS in those early days was extremely beneficial to building the successful UK Charity we have to day. TMS was instrumental in sending to me Mastocytosis information, much of it by snail mail in those days, and giving me good advice about starting my group. We now have 300 members and have held very successful UK conferences attended by many extremely knowledgeable mast cell specialists. Our group is now recognised all over world with many international doctors and patients contacting us for help and advice.

I am very pleased to let everyone know our group has appointed on my retirement two Co-Chairs, Jess Hobart and Dawn Brogden, who will share being Chair of our group. I am extremely confident both Dawn and Jess will continue to advise, help and support group members.

My very grateful thanks to TMS for helping me get our UK Mastocytosis Charity off the ground and enabling me to be in touch with so many amazing people.”
Donations

RESEARCH DONATIONS

Jaime Miller
In Honor of Zaid Petitt-Clark
Shannon Catalano
In Honor of Wyatt Catalano
Jenna Rice
Robert Johnson
In Honor of Gideon Smith
William Cahill
In Honor of Gideon Smith
Rajesh Shrestha
In Honor of Gideon Smith
Craig Clarlelli
In Honor of Gideon Smith
Bach College
In Honor of Gideon Smith
Claire McGee
In Honor of Gideon Smith
Yessenia Henry
In Honor of Gideon Smith & Lumarys Montijo
Lana J Lundt
In Memory of Janet Brash
Sister Judy MacDonell
In Honor of Nephew
Sohlaug Grafik
SARAH GITTLEMAN
MEMORIAL FUND
Barbara Gittleman
Memory of Irv Caplan
Ilene Gittleman
In Memory of Irv Caplan
Shelly Rossmore
In Memory of Irv Caplan
Anonymous
In Memory of Irv Caplan
Rochelle Schwartz
In Honor of Andria Weiss
Rochelle Schwartz
In Memory of Irv Caplan
Bonita Bohl
Honor of Neal Victory’s Birthday

GENERAL CONTRIBUTIONS

QVC
Pam & Daniel Hodge
John D Bray, MD
David Elkayam MD
Meredith Lee Heltzer, MD
Phillip L Lieberman, MD, FAAAAI
C. Ross Westley, MD, FAAAAI
Marjorie Lee Slankard, MD, FAAAAI
Amit Kaura
Tracey Schwartz
Canterbury School
Philip W Askenase, MD, FAAAAI
Andrew A Bagg, MD, FAAAAI
Nancy Cummings, MD, FAAAAI
Renata J Engler, MD, FAAAAI
Ronald A Simon, MD, FAAAAI
Franklin Yamamoto, MD, FAAAAI
Rebecca Monday
Amazon Smile
Rebecca Monday
igive.com
Rebecca Monday
igive.com
Suzanne Johnson
Sarah Dane Sperry
Robert Narva
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Coral Springs Charter School
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Rebecca Monday
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Nicholas & Barara Campagna Jr.
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ANGEL FUND CONTRIBUTIONS

Therese & Terry Lambert
Robin & William Charlton
Stanley & Penny Boney
Ken & Patti Williams
Nancy Russell
Stephen Uebelhor
Juliann & William Johnston
Shirley & Carl Moores
Ryan Prince
Robert & Rita Kelly
Janet Nordstrom
Craig Ewart
Susan Seaman
Rebecca Solberg
Alan Guttman
Sarah & Paul Vizcaino
Sherry Lindley
Lisa-Marie Bolognese
Harvey & Arlene Goldstein
Daniel & Wendy Stekloff
Ellen & Robert Stewart
Ralph & Linda Guerin
Dr. Kent Schauer
The Mastocytosis Society Membership

RESEARCH + EDUCATION + ADVOCACY

There are many benefits of membership, including:

• **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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### 2015 Supporting Members*

<table>
<thead>
<tr>
<th>Name</th>
<th>Membership Level</th>
</tr>
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<tbody>
<tr>
<td>Stephanie O Oelrich</td>
<td>Copper Membership</td>
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<tr>
<td>Andrew Bothwell</td>
<td>Copper Membership</td>
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<tr>
<td>Eileen Buss</td>
<td>Copper Membership</td>
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<tr>
<td>Keith Parker</td>
<td>Copper Membership</td>
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<tr>
<td>Geri Brooks</td>
<td>Copper Membership</td>
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<tr>
<td>Phyllis Gangel-Jacob</td>
<td>Copper Membership</td>
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<tr>
<td>Jill &amp; Ken Shuck</td>
<td>Copper Membership</td>
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<tr>
<td>Mark Rios</td>
<td>Copper Membership</td>
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<tr>
<td>Ronald &amp; Lisa Simmons</td>
<td>Copper Membership</td>
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<tr>
<td>Andrew &amp; Valerie Slee</td>
<td>Copper Membership</td>
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<tr>
<td>Rebecca Runo</td>
<td>Copper Membership</td>
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<tr>
<td>Dawn Rodriguez</td>
<td>Copper Membership</td>
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<tr>
<td>T. L. &amp; Judy. M. Thompson</td>
<td>Copper Membership</td>
</tr>
<tr>
<td>Arthur &amp; Georgia Diefendorf</td>
<td>Copper Membership</td>
</tr>
<tr>
<td>D.K. Selover</td>
<td>Silver Membership</td>
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<tr>
<td>Barbara J Kinney</td>
<td>Silver Membership</td>
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<tr>
<td>Dr. Kent Schauer</td>
<td>Silver Membership</td>
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<tr>
<td>Susan &amp; Dr. Lowell Yadan</td>
<td>Silver Membership</td>
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<tr>
<td>Anthony Rossi</td>
<td>Silver Membership</td>
</tr>
<tr>
<td>Judith &amp; Dennis Sleighter</td>
<td>Silver Membership</td>
</tr>
<tr>
<td>Michael Harad,</td>
<td>Upgrade to Gold Membership</td>
</tr>
<tr>
<td>James &amp; Betty McKee</td>
<td>Gold Membership</td>
</tr>
<tr>
<td>Martha &amp; James Grant</td>
<td>Gold Membership</td>
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<tr>
<td>Michael Harad,</td>
<td>Gold Membership 2016</td>
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<tr>
<td>Debra Schankweiler</td>
<td>Gold Membership</td>
</tr>
<tr>
<td>Roberta Warren</td>
<td>Platinum Membership</td>
</tr>
</tbody>
</table>

Support Levels: $75 Copper, $150 Silver, $250 Gold, $500 Platinum, $1,000 Titanium

*Members who have given beyond their annual $35 dues when renewing their membership or starting a membership are considered Supporting Members. (This list does not include those who made major contributions to other initiatives/funds such as the Walk-a-thon or the TMS Conference, but rather designates different levels of donations made at time of membership dues.)
Membership Application Form

ANGEL FUND WAIVER

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 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 for your dues to be paid through the “Angel Program” due to financial hardship, please 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 ____
TMS DVD ORDER FORM

Shipping information (please type or print clearly):

Name: ____________________________________________

Address: ____________________________________________

City: _______________ State: ___________ Zip: ______________

Country: ___________ Phone: ______________ Email: ______________

<table>
<thead>
<tr>
<th>Description</th>
<th>Quantity</th>
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<th>Total</th>
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<tr>
<td>2005 &amp; 2006–2 year set (limited avail)</td>
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<td>2011 – 4 DVD set (Massachusetts)</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.

<table>
<thead>
<tr>
<th>Shipping</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>$20.00 Int’l (DVD sets)</td>
<td></td>
</tr>
<tr>
<td>$6.00 USA (DVD sets)</td>
<td></td>
</tr>
<tr>
<td>$1.00 USA (Magnets)</td>
<td></td>
</tr>
</tbody>
</table>

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 129, Hastings, NE 68902-0129.
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 )

Check Enclosed _____ Money Order Enclosed _____ Paid Online _______


Would you like to double your annual contribution to include a donation to the Angel Fund for individuals with a mast cell disease 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)

Make check or money order payable to The Mastocytosis Society, and send to:

The Mastocytosis Society, c/o Treasurer, P.O. Box 129, Hastings, NE 68902-0129

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 for your dues to be paid through the “Angel Program” due to financial hardship, 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 ______

The Mastocytosis Society, Inc., PO Box 129, Hastings, NE 68902-0129
The Mastocytosis Chronicles
P.O. Box 129
Hastings, NE 68902

Return Service Requested

Visit the Mastocytosis Society website at www.tmsforacure.org

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 129
Hastings, NE 68902
or pay by PayPal at www.tmsforacure.org

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!

Become A Supporting Member

Unsure When Your Membership Expires?