LIFE WAS PERFECT
By Judith Friedman

In the days when life was fine and the sun shone bright,
We laughed and planned and dreamed.
We danced in the warmth of love.
We believed that life was perfect.
Then, our eldest daughter, Sarah became ill.
We didn’t realize what the diagnosis would come to mean.
Nothing very bad could happen to us.
We believed that life was perfect.
I do not have to see your face to remember your sweet smile.
I do not have to hug you, although if I could, I would.
I do not have to hear your voice, our love is understood.
We grew together, nurtured with love.
We believed that life was perfect.
Sometimes love and hope and medicine Do not make an illness disappear.
Sometimes the unimaginable happens,
And we are left wondering what happened to,
The life that was perfect...
About Us

Our Mission
We are dedicated to providing multi-faceted support to patients, families and medical professionals in our community and to leading the advancement of knowledge and research in mast cell diseases through education, advocacy and collaboration.

Our Vision
Transforming lives of patients and families while finding a cure for mast cell diseases.

Submissions
The Mast Cell Disease Chronicles is a semiannual publication produced by The Mast Cell Disease Society, Inc. (TMS) for the greater mast cell disease community. If you have questions about the content of the publication or would like to submit an article for publication, please email us at chronicles@tmsforacure.org.
Early spring greetings!

All of us at The Mast Cell Disease Society, Inc. (TMS) are bursting with excitement as we move forward with numerous new initiatives and projects! Having our Executive Director, Lauren Denton, lead us since September 2020 has been a transformative experience. She has allowed us to not only envision a more comprehensive plan that better serves all patients, families, physicians and investigators in our mast cell disease community, but has also provided us with a solid fundraising platform which is already demonstrating success in supporting our goals. She has guided us to committing to a strategic plan that will result in more of everything—research, education of both physicians and patients, dynamic support group forums both online and in-person, and advocacy for patients/families in their communities as well as on Capitol Hill.

We hope that more of you will want to join us as dedicated volunteers and get involved in our compelling work. And, as always, donors are the backbone of non-profits like TMS, and allow our work to continue.

We look forward to seeing the results of our efforts on your behalf. I have never been so excited about what we are currently doing, and what we are planning to accomplish over the next 3 years!

Warmly,

VALERIE M. SLEE, RN, BSN
CHAIR, BOARD OF DIRECTORS
Diagnosed in her early twenties with a rare disease called mastocytosis, Katie refused to be defeated. Her journey began when she started experiencing many confusing symptoms including heart palpitations, headaches, flushing, dizzy spells, abdominal pain, congestion, and life-threatening anaphylaxis. After a host of doctor’s visits and tests, she learned that she had an inflammatory condition called mastocytosis. This condition causes the body to produce excess amounts of mast cells, a type of white blood cell responsible for producing histamine and other inflammatory substances. In short, it triggers a lot of inflammation and effects your whole body, causing it to be very reactive to many different stimuli.

Although initially it was difficult to accept that she had an incurable disease, Katie was not willing to believe that taking medications and feeling sick the rest of her life was her only option. She also realized that her diagnosis was not just about herself. She needed to find solutions.

"She needed to find solutions so she could help others who were struggling with the same issues."

Although initially it was difficult to accept that she had an incurable disease, Katie was not willing to believe that taking medications and feeling sick the rest of her life was her only option. She also realized that her diagnosis was not just about herself. She needed to find solutions. She drastically changed her diet to focus on nutrient-dense, whole foods and spent hours researching and learning about her condition and ways to support her body naturally. Having reversed many of her symptoms, Katie now stays active, enjoying horse-back riding, running, and hiking. She is always ready to take on a new challenge.

FINDING HER PURPOSE
Katie completed training to become a nutritional therapist and spent many hours in the kitchen developing anti-inflammatory recipes to share with others. Katie loves working as a nutritional therapist, helping others meet their health goals, and live fuller, more vibrant lives despite challenges. Instead of allowing defeat, Katie has shown that a disease like mastocytosis can open a door to unforeseen growth and opportunity.
WHY DOES TMS CONDUCT SURVEYS OF THE MEMBERS OF THE MAST CELL DISEASE COMMUNITY?

BY VALERIE M. SLEE, RN, BSN AND SUSAN JENNINGS, PHD, RESEARCH CO-CHAIR

The TMS Research Committee has done several surveys over the last decade. What is the purpose of conducting such research surveys? How do the results of these surveys help us to meet the goals of our TMS mission, which include research, education, support and advocacy for patients, families and the physicians who treat us?

Surveys are a very concise way of gathering information relative to a particular topic. For TMS, patient surveys are an organized way for us to identify the unmet health and healthcare needs of our mast cell disease (MCD) community, such as identifying differences in the use of testing for diagnosis, examining the perceived success of different
treatment modalities, and evaluating the overall quality of life for patients affected by MCDs. We can also identify gaps in access to care, needs for greater education and training, and trends in utilization of different sets of diagnostic criteria. All of this information is analyzed and discussed by members of the Research Committee in collaboration with our physicians, and then submitted for publication in a peer-reviewed journal so that the experiences and perspectives of patients can be shared with a wider audience and made accessible to the public. Key goals of conducting the surveys are to make significant changes in what we do as an organization to meet the unmet needs identified in the survey data, to ensure that specialist physicians have the information necessary to be able to consider patient experiences when they meet to discuss patient care, and to provide resources for anyone engaged in mast cell disease advocacy. The ultimate purpose is the overall improvement in care and quality of life for our patients and families.

For example, we conducted a survey on mast cell activation syndrome (MCAS) in preparation for an NIH workshop on MCAS in September 2018. The data we analyzed astounded even those of us who had MCAS!

“We learned that patients with MCAS experienced having their usual activities limited by physical or mental health an average of 14.9 out of 30 days per month. This contributed greatly to the recognition that living with symptoms of mast cell activation can be chronically disabling. Because patients with mastocytosis and hereditary alpha tryptasemia (HaT) may also experience symptoms of mast cell activation as part of their disease, this potential for chronic disability may apply to other mast cell diseases. Here is an example of how research into one variant of mast cell disease yielded data that has the potential to ultimately help those with a different mast cell disease diagnosis.

It is important to recognize that in our mast cell disease community, we have many physicians who choose to utilize different diagnostic criteria than the ones which TMS supports (please see these reference articles for criteria TMS supports). First of all, let us review TMS’s position statement on diagnostic criteria:

TMS supports the Consensus Criteria for mastocytosis and the Proposed

"The data we analyzed astounded even those of us who had MCAS!"
Consensus Criteria for mast cell activation syndrome (MCAS) from Valent et al., both of which were scheduled for a review/revision during the combined European Competence Network on Mastocytosis (ECNM) Annual Meeting/Working Group Consensus Conference in Vienna in August 2020. These criteria are not perfect, as no criteria are, but they are well documented, frequently reviewed and based on sound research. Patients may seek care from physicians utilizing alternative criteria for many different reasons. TMS understands the immense difficulties that many patients with mast cell disease endure. While TMS cannot endorse alternate criteria, we support all patients and caregivers, and their inherent right to choose the care which they feel is appropriate, and ultimately helpful, for them in relieving their pain and suffering and improving their physical, social and mental health.

TMS is extremely interested in learning how patients are diagnosed with a mast cell disease, meaning what types of evaluation tools were utilized, such as a full history and physical exam, a symptom/trigger list, which lab tests or procedures were ordered and which were used to confirm a diagnosis, and what routine follow up testing is used to track the course of the disease. As we move towards establishing a patient registry, information like this will guide us in looking at what type of registry we will require. As always, TMS is equally committed to mastocytosis and all of its variants (CM, SM, SSM, ASM, SM-AHN, MCL)³, mast cell sarcoma, all forms of MCAS, and HaT.

"TMS is equally committed to mastocytosis and all of its variants (CM, SM, SSM, ASM, SM-AHN, MCL)³, mast cell sarcoma, all forms of MCAS, and HaT."

Participation in a survey gives us direct patient voice input (or in the case of a child, parent voice input). This strongly endorses our core value of Patients First and provides us with an opportunity to hear current concerns and needs. We have a team of dedicated survey specialists, under the direction of Susan Jennings, PhD, Research Chair, in collaboration with Angela Bowman, PhD, Principal Investigator, who set up many of our surveys and analyze the data with others on the survey team. We work closely with our physicians on both the survey design, and in writing the papers we submit for publication from the data analyzed.

The TMS Research Committee is currently writing a paper on the results of the 2018 survey on MCAS. Pending will be papers on the Needs Assessment Survey and the COVID-19 Survey, both conducted in 2020. We were also asked to coordinate writing a paper in collaboration with other patient groups around the world on the Greatest Needs and Concerns of Patients in our respective countries. We are busy compiling the data from many different countries and begun writing this paper.
References:

1. https://tmsforacure.org/tms-research-committee-publications-and-presentations/
At Blueprint Medicines, we work together with the patient community in pursuit of one common goal: to dramatically improve the lives of people with genomically defined cancers and rare diseases.

We strive to combine a deep understanding of the genetic blueprint of cancer and rare diseases with the expertise to craft precision therapies. With this approach, we aim to develop breakthrough medicines that allow patients to live longer, healthier lives.

Blueprint Medicines is thankful to SM patients and caregivers for their invaluable collaboration and insights, and to patient advocates for their unwavering commitment to supporting patients during their SM journey. Blueprint Medicines is proud to be the Titanium Partner in Hope of The Mast Cell Disease Society and we look forward to continuing our work together.

To learn more about Blueprint Medicines, go to:

blueprintmedicines.com/patients

SYSTEMIC MASTOCYTOSIS AMBASSADOR PROGRAM
There’s strength in connecting.

SM AMBASSADOR
KRISTINE

SM AMBASSADOR
SARAH

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TERI

The Systemic Mastocytosis (SM) Ambassador Program, developed by Blueprint Medicines, is a patient education program for people living with SM and their caregivers. SM Ambassadors will share their journey, including diagnosis and living with SM, through virtual programs and live speaking engagements.

Like the SM Ambassador Program on Facebook

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The Mast Cell Disease Society, Inc. (TMS) is excited to continue our partnership with the American Academy of Allergy, Asthma and Immunology (AAAAI) in offering the 2021 AAAAI/TMS Research Award in Mast Cell Disorders including Mastocytosis and/or Mast Cell Activation Syndrome. The RFP was released in 2020 and due in November 2020. This year’s award was presented at the AAAAI 2021 Virtual Awards Celebration on February 26, 2021 to Dr. Daniel Dwyer with Brigham and Women’s Hospital (BWH) to conduct studies on “Single-cell characterization of cutaneous mast cells in mastocytosis and hereditary alpha-trypasemia.”

Dr. Dwyer will focus on applying his groundbreaking work using single-cell RNA sequencing to understand mast cell heterogeneity and biology to mast cells residing in the skin of patients with mastocytosis and hereditary alpha-trypasemia. Studies will also include an evaluation of the activation status of skin mast cells from such patients.

This basic science research will be conducted in close collaboration with clinicians at the BWH Mastocytosis Center, allowing elucidation of the link between transcriptional alterations in mast cells from patients to clinical manifestations of each disease, potentially leading to the development of new therapeutic approaches for the management of mast cell diseases. Data obtained from this study is intended to be used in combination with an ongoing study conducting single cell RNA-sequencing on mast cells from mastocytosis patient bone marrow as the foundation for an R-01 grant application to the National Institutes of Health, focused on developing a deeper, mechanistic understanding of human mast cell diseases.

The environment at BWH and Harvard Medical School is among the best in the world for studying human mast cell diseases. The BWH Mastocytosis Center, headed by Dr. Mariana Castells, is a nationally recognized Center of Excellence that brings together allergists, immunologists, pathologists, and other specialists needed to treat the many aspects of mast cell diseases. They have developed a database that contains information that will facilitate segmentation of phenotypes of mast cell diseases, and a robust referral base that provides necessary clinical samples.

We congratulate Dr. Dwyer on receiving this award!
MANY SQUARES TO SEW

At age 23 Sarah had barely begun to write the story of her life when she passed away from mast cell leukemia. More than a decade later, her legacy continues on through funds raised to support research and awareness of mast cell disease in hope that one day we find a cure.
Sarah was a typical 23 year old, who was a Michigan State graduate in accounting and wanted to be a CPA. On February 21, 2004 the Gittleman family’s life changed forever. Their daughter, Sarah, had an anaphylactic reaction to medication and almost died. During her recovery she received a diagnosis of Systemic Mastocytosis. Not knowing what that meant at the time, Sarah and her family found out quickly. Within the next four months her symptoms were rapidly increasing and by July, Sarah was diagnosed with Mast Cell Leukemia. Sarah passed away on December 21, 2004.

In 2005 the Sarah Gittleman Research Memorial Fund was established in Sarah’s memory by her family.

“As a Family, we wanted there to be a way to honor and remember Sarah. Since finding a cure is the most important thing to us we decided to create a research fund in Sarah’s
name," says the Gittleman family.

Three years later, 2008 marked the first TMS walk-a-thon benefitting this fund. Hung in the hallway of the recreation center where people registered, was a memory quilt about Sarah that her mother made. The quilt tells a little bit about Sarah’s life.

For over a decade, the Gittleman family and mast cell disease community have raised tens of thousands to support the advancement of research in the hopes one day we find a cure for others living with a mast cell disease.

"I feel that as a parent who had lost a child to this devastating disease (mast cell leukemia) it is my obligation to help bring awareness to the community about mast cell diseases," says mother Barbara.

"... it is my obligation to help bring awareness to the community about mast cell disease," says mother Barbara.

TMS and the Gittleman family are very grateful for the generosity of those who celebrated Sarah’s 40th on March 12th and contributed to advancing our understanding and research of mast cell disease.

Sarah’s story continues on, through the compassion of our community and those who remember her beautiful smile and warm heart. There are many squares left to sew in this story.

“Our hope is that someday a cure will be found and no one will ever have to suffer or lose a loved one from this devastating disease," said Sarah’s family, Barbara, Ted and Laura.

HAPPY 40TH BIRTHDAY SARAH.
HOW TO TALK TO YOUR PHYSICIAN AND BE HEARD

You have been waiting for this appointment for months, whether it is in person or by telemedicine, and you are anxious to get started and have all of your questions answered. You wonder if you will like this physician, if you will “hit it off” with them, and if you will finally find someone who understands the complexities of mast cell diseases. 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!

BY VALERIE M. SLEE, RN, BSN, TMS CHAIR

Before the day even arrives, you need to begin preparations. If this is a telemedicine visit, make sure you know how to sign on to the appointment on your phone or computer. Type, save and print a sheet with your name, address, phone number, email, all current diagnoses and all current allergies, or make sure you have this information available for your televisit.

Next to each allergy, state what happens to you if you take the drug or food (e.g., 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 and why you are taking them. 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 concerns 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 be present at the appointment. 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....

"First of all, understand that you have 15 minutes or less for this entire appointment."

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 them 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.”

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 them: “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 they are 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? To get a prescription refilled?
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 prepare copies if the physician would like to have them. 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 them, 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 masto-strong!

References:

SOCKS FOR A CURE

2021 marks the 5th year anniversary of the passing of our beloved mother to complications from her mast cell disease and other comorbid conditions. The Mimi’s Sunshine Fund was established in 2018 in her honor to provide hope and accelerate the advancement of mast cell disease and comorbidity research to help find cures for the ones who continue to battle for their life. During the daily ups and downs of living with debilitating chronic disease, silly matching socks became our secret superpower connecting us in our hardest moments and giving us comfort and strength.

Each year on her Birthday, May 17th, friends and family have worn silly socks and sent their happy feet photos to celebrate her incredible
spirit and the joy and laughter she brought to our world. This year, we wanted to make her Birthday that much more special and are excited to be releasing two very special socks with a goal of raising $10,000 for much needed research. With over 44% of mast cell disease patients having one or more comorbidity conditions, together we can transform lives.

"With over 44% of mast cell disease patients having one of more comorbidity conditions, together we can transform lives."

This May 17th, we invite our entire mast cell disease community to join us in wearing silly socks, so you can feel the magic of knowing we are all connected on this day, lifting each other up and reminding us all that we are not alone.

SHARE YOUR HAPPY FEET
To share photos of your happy feet and to be included in our sock collage please email: fundraising@tmsforacure.org.

START A FUNDRAISER
If you would like to start fundraiser, visit: pages.donately.com/tmsforacure or contact us at: fundraising@tmsforacure.org with your story and goals to make a difference.
Estate planning has little to do with anyone’s net worth, and it’s a great exercise for all of us. If you’ve worked hard in life, you deserve to experience the deep satisfaction of directing what happens to your resources after you are gone. This process of making decisions and documenting distribution of assets to your heirs and the causes you support is the essence of estate planning.

Here are six easy steps to put you on a path to leaving your legacy:

1. **DOCUMENT YOUR ESTATE.**
   Start by creating a clear, comprehensive list of all your assets, including real estate, investments, retirement plans, life insurance, and personal property. Add these together and subtract your debt.

2. **LIST THE PEOPLE AND CHARITABLE ORGANIZATIONS YOU WISH TO REMEMBER IN YOUR WILL.**

3. **ASSESS YOUR FINANCIAL NEEDS.**
   Think about whether you have adequate income to support yourself and your family for the remainder of your life and put plans in place to help that happen.

4. **SECURE THE ASSISTANCE OF ONE OR MORE ADVISORS.**

5. **PLAN OTHER IMPORTANT DETAILS.**
   This is a good time to name an executor of your estate, establish a living will, and designate a power of attorney. Share a copy with your executor and let family members know where your will is kept.

6. **IF YOU INCLUDE A GIFT TO A CHARITY IN YOUR WILL, LET THEM KNOW.**
   At The Mast Cell Disease Society (TMS), we are profoundly grateful for bequests. Too often, though, we receive these gifts unexpectedly, without the chance to say “thank you” in person. If you decide to make a provision in your will for TMS, or any other charity, please share the news of your generous intentions.

Please visit www.tmsforacure.org/legacy or contact us at fundraising@tmsforacure.org for more information about our Legacy Society and giving a gift.
I HAD THE RIGHT FRIEND

It was late July, 2006, when my wife and I were burning up reward tickets on a three day weekend in Tampa Bay, FL. We somehow found ourselves in the Hard Rock Casino. When, in a millisecond, it felt like someone poured gasoline on my head and lit the match. It was fast and furious. My first thought was, “I don’t want to die in Tampa, I want to die at home, in Albuquerque.”

My first thought was, “I don’t want to die in Tampa, I want to die at home, in Albuquerque.”

I immediately took three Benadryl. I then began having trouble swallowing. My wife asked for an ambulance. By the time it showed up, I realized that my airway was not going to shut off. And, I declined the ride.

I was carrying Benadryl because the night before, at a ballgame, I had experienced a much milder version of that event, without the swallowing difficulty. I found an attendant, with Benadryl which seemed to resolve things in about 15 minutes. Two weeks prior to that, after eating something I would normally not have eaten, my head began tingling. That feeling traveled from my head to my feet and then back up to my head, and left my body. It was bizarre, but I just assumed that I must have been allergic to what I had eaten.

We left the Hard Rock and went back to the hotel.

I called my friend, allergist-immunologist, Mike Clayton. I told him that I would be back home the next day and I needed to have epinephrine waiting for me and that he needed to figure out what I was allergic to.

I do not remember the exact sequence but Mike put me on an elimination diet and prednisone. I was still taking lots of Benadryl. Before long, I stopped eating and things were going from bad to worse. Since riding my bicycle usually made things better, I went on a ride and created an acute asthma attack. That evening, I went to sleep thinking that if I did not wake up, it would be fine. I was surprised to wake up breathing fine. Mike then put me on asthma meds.
At some point, Mike called to tell me that he did not think that I was allergic to anything, but feared that I had systemic mastocytosis. He later told me that he had seen one case before. He asked the lab for tryptase levels and said they were high. He then scheduled a bone marrow biopsy with a hematologist.

My hematologist, a genuinely sweet man, said that he had been reading up on the disease and did not think that I had it nor that I needed a bone marrow biopsy. Even though I had heard horror stories about the procedure, I insisted on having it done, putting all of my trust in Mike. It turned out that my friend was right. I should note that I went out to play golf after the biopsy with a zero pain level, even after the lidocaine wore off.

I began eliminating things that caused my head and shoulders to flush, especially when it was followed by difficulty swallowing. And, in a relatively short time, I had identified my triggers. They were scents, things I ate (everything processed), stress, and heat. That first winter, I was only comfortable and asymptomatic for a few minutes after awakening and while riding my bike at night in the cold.

In order to avoid my triggers, I stopped traveling commercially, eating out, (I still eat the same thing everyday with little variation), being around people, and talking politics with my liberal daughter. Over the years, I continue to improve. My exquisite sense of smell is no longer that great and heat no longer bothers me.

My friend, Mike Clayton, was very wise and kind and very much missed by those of us who were fortunate enough to know him. Five years ago, around Thanksgiving, he passed away suddenly, at the age of 64, while jogging with his dog. I am convinced that I would not be on this earth if it were not for him.

“I am convinced that I would not be on this earth if it were not for him.”

KEN T SCH A U ER
thank you.

TO OUR SUPPORTERS

Our Partners in Hope, Legacy Society, and Golden Circle recognize the critical role of philanthropy in sustaining our organization to serve generations to come. Gifts to The Mast Cell Disease Society ensures that we continue to support all members of our community and advance research of mast cell diseases. We are grateful for the special commitment shown by these members.

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A Heartfelt Thank You to Our Healthcare Heroes

While many of us continue to work from home, you continue to deliver high-quality care to patients and families affected by mast cell disease.

In these uncertain times, you continue to rise to the challenge, and you reassure us that science, knowledge and compassion will lead us to a healthier tomorrow.

TMS extends a heartfelt thank you to healthcare heroes throughout the nation and beyond.

As an organization, who predominantly serves vulnerable populations, we are committed to modeling diversity and inclusion for the entire community whatever their gender, race, ethnicity, national origin, age, sexual orientation or identity, education or disability, and to maintaining an inclusive environment with equitable treatment for all. We respect and value diverse life experiences and heritages and ensure that all voices are valued and heard.

The Chronicles is a semiannual publication for the global mast cell disease community. If you have questions about the content of the publication please email us at chronicles@tmsforacure.org.

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