THE MAST CELL DISEASE SOCIETY
24TH NATIONAL CONFERENCE
2021

OCTOBER 13-20
Virtual
One Week Dedicated to Mast Cell Diseases

PRESENTING SPONSOR BLUEPRINT MEDICINES
Welcome!

We are excited to have you join us for our 24th National Conference. For the next week, you can expect medical presentations on specific mast cell diseases, including updates on the latest research, wellness workshops, panel discussions with leading experts, and a variety of options to connect with one another through support group activities on our virtual platform. This is our largest event yet stretching across the US, and internationally! We hope you enjoy the week and are able to connect with others in our rare disease community.

Lauren Denton, MA
Executive Director

Valerie M. Slee, RN, BSN
Chair, Board of Directors

SPECIAL THANK YOU TO OUR PARTNERS IN HOPE & SPONSORS!

TMS
THE MAST CELL DISEASE SOCIETY, INC.

P.O. Box 416, Sterling, MA 01564
www.tmsforacure.org

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.

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

Values
Integrity
Excellence
Compassion
Inclusion
Commitment
Teamwork
Transparency
Stewardship

Board of Directors
Valerie Slee
Chair
Celeste Finnerty
Vice Chair – Research
Jan Hempstead
Vice Chair – Education & Patient Support
Courtney Rabb
Vice Chair – Community Engagement
Rosemary Schultz
Interim Treasurer
Judith Emmel
24th National Conference
User Guide

VIRTUAL PLATFORM- WHOVA
- Login with the email you registered with.
- Use Google Chrome if possible to best utilize Whova.
- If you are having issues logging in, try the following tricks:
  - Restart your computer
  - Clear your cashe (history)
  - Email sarah@yourvipevent.com to have your questions answered
- Once in the platform, you can access the live-stream under agenda. Click on the session you would like to attend.
- Use the chat box to interact with other attendees.
- Visit the sponsor and exhibitor booths in the menu bar on the left hand side of the screen.

RECORDINGS
Will be available within 24 hours after the session to watch on-demand in Whova. You can re-watch session videos until December 2021 using your Whova login.

SPEAKER BIOS
We are grateful for all our speakers to give their time and expertise! You may learn more about each speaker by visiting the "Speaker" section in Whova.

JOIN THE CONVERSATION
Engage with us on Whova & Social Media!
Visit Community in Whova to video chat 1:1 or in a group, join a discussion board, and more. There will be support groups available throughout the conference. For the most up-to-date schedule visit www.tmsforacure.org

#2021TMSCONFERENCE
#TMSFORACURE

SUPPORT GROUPS
TMS support groups are a great way to join and build community! Our leaders this week will be hosting groups for newly diagnosed patients, parents of children with mast cell disease, teens, young adults, men's group, pet lovers and much more. You may find them listed in this program, on Whova, as well as at: https://tmsforacure.org/resources/support-group-meeting/

Support groups require separate pre-registration (free) due to patient privacy, which a unique link will be sent to your email. We look forward to you joining us!

SESSION & EVENT EVALUATION
At the end of each day, please fill out evaluations for each session you attended. There will be an additional post-event survey sent out after the conference. Thank you for providing your feedback, this will help us for future events!
PHOTO/VIDEO DISCLAIMER

The Mast Cell Disease Society (TMS) reserves the right to use any photograph/video taken or posted, without the expressed written permission of those included within the photograph/video. TMS may use the photograph/video in publications or other media material produced, used or contracted by TMS including but not limited to: brochures, invitations, books, newspapers, magazines, television, websites, etc.

To ensure the privacy of individuals and children, images will not be identified using full names or personal identifying information without written approval from the photographed subject, parent or legal guardian.

A person attending the TMS event who does not wish to have their image recorded or distributed, should make their wishes known to the event organizers at TMS in writing of his/her intentions and include the photograph. TMS will use the photo for identification purposes and will hold it in confidence.

By participating in a TMS event or by failing to notify TMS, in writing, your desire to not have your post used by TMS, you are agreeing to release, defend, hold harmless and indemnify TMS from any and all claims of involving the use of your picture or likeness.

Thank you for your understanding and cooperation

Ways to Give

There are many ways to give and make a difference for our rare disease community to support our education, support, or strategic research grantmaking efforts.

Volunteer
Find meaningful volunteer opportunities with TMS as a support group leader, committee member, advocacy or fundraising.

Shop to Give
Through Amazon Smiles or our Bonfire Shop for TMS Merchandise, your support will go towards our vital work.

Donate Today
We accept Online, Matching Gifts, Stock Giving & Corporate Giving

Join our Giving Societies
Golden Circle & Planned Giving Society for leadership gifts.

www.tmsforacure.org/give
We aim to make real the promise of precision medicine with a goal to improve and extend life for as many people as possible.

Blueprint Medicines Global Headquarters
45 Sidney Street
Cambridge, MA 02139
USA

Blueprint Medicines (Switzerland) GmbH
Baarerstrasse 8
6300 Zug
Switzerland
OPENING REMARKS
9:00am - 9:15am / Lauren Denton, MA, Valerie Slee, RN, BSN & Kate Haviland

WHAT IS MAST CELL DISEASE?
9:20am - 9:55am / Valerie Slee, RN, BSN

WHAT IS MAST CELL DISEASE Q&A
10:00am - 10:25am / Valerie Slee, RN, BSN and Susan Jennings, PhD

BONE MARROW BIOPSIES & PATHOLOGY IN PATIENTS WITH SYSTEMIC MASTOCYTOSIS
10:30am - 10:55am / Tracy George, MD

GASTROINTESTINAL BIOPSY PATHOLOGY IN PATIENTS WITH SYSTEMIC MASTOCYTOSIS: IS THE NUMBER OF MAST CELLS PER HIGH POWER FIELD DIAGNOSTIC?
11:00am - 11:25am / Jason L. Hornick, MD, PhD

INDOLENT SYSTEMIC MASTOCYTOSIS INCLUDING CURRENT TREATMENTS
11:30am - 11:55am / Matt Giannetti, MD

SYSTEMIC MASTOCYTOSIS Q&A
12:00pm - 12:45pm / Tracy George, MD

BREAK 12:45 PM - 2:00PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

UPDATES IN PEDIATRIC CUTANEOUS AND SYSTEMIC MASTOCYTOSIS
2:00pm - 2:45pm / Melody Carter, MD

PEDIATRIC CUTANEOUS & SYSTEMIC MASTOCYTOSIS Q&A
3:00pm - 3:45pm / Melody Carter, MD

PURE ADULT CUTANEOUS MASTOCYTOSIS
4:00pm - 4:25pm / Mariana Castells, MD, PhD

SUPPORT GROUP - PARENTS OF CHILDREN WITH MAST CELL DISEASE*
4:00pm - 6:00pm / Leaders: Valerie Slee and Celeste Finnerty

*Separate registration required. Link in Whova session or at tmsforacure.org.
24TH NATIONAL CONFERENCE 2021

DAY 2

Thursday, October 14, 11:00am-3:30pm ET

TAPPING & GUIDED MEDITATION
11:00am - 11:20am / Jan Marie Smith

BREAK 11:20AM - 12:00 PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

UPDATES EFFECTIVE TREATMENTS FOR MCAS
1:30pm - 1:55pm / Mariana Castells, MD, PhD

MYELOPROLIFERATIVE NEOPLASMS ASSOCIATED WITH SM (SM-AHN)
2:00pm - 2:25pm / Deepti Radia

TREATMENT OPTIONS FOR ADVANCED SYSTEMIC MASTOCYTOSIS
2:30pm - 2:55pm / Jason Gotlib, MD, MS

UPDATES IN STEM CELL TRANSPLANTS AS A TREATMENT OPTION FOR ADVANCED DISEASE
3:00pm - 3:25pm / Celalettin Ustun, MD

SUPPORT GROUP - NEWLY DIAGNOSED*
12:00pm - 1:00pm / Leader: Jan Hempstead
*Separate registration required. Link in Whova session or at tmsforacure.org.

SUPPORT GROUP - ADULTS WITH MCAS*
7:00pm - 9:00pm / Leaders: Valerie Slee and Celeste Finnerty
*Separate registration required. Link in Whova session or at tmsforacure.org.
<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30am - 9:45am</td>
<td>BREATHING TECHNIQUES</td>
<td>Jan Hempstead, RN</td>
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<tr>
<td>10:00am - 10:25am</td>
<td>USES AND LIMITATIONS OF SERUM TRYPPTASE LEVELS IN MAST CELL DISORDERS</td>
<td>Larry Schwartz, MD, PhD</td>
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<tr>
<td>10:30am - 10:55am</td>
<td>UPDATES IN THE USE OF URINARY MARKERS IN DIAGNOSING MAST CELL DISEASE</td>
<td>Joseph Butterfield, MD</td>
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<tr>
<td>11:00am - 11:25am</td>
<td>PERIOPERATIVE MANAGEMENT OF MAST CELL DISEASE, INCLUDING DRUG ALLERGIES</td>
<td>Mariana Castells, MD, PhD</td>
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<tr>
<td>11:30am - 11:55am</td>
<td>PREGNANCY IN MAST CELL DISEASE</td>
<td>Anna Kovalszki, MD</td>
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<tr>
<td>12:00pm - 12:45pm</td>
<td>MAST CELL DISEASE Q&amp;A WITH DR. CASTELLS</td>
<td>Mariana Castells, MD, PhD</td>
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<tr>
<td>12:45pm - 2:00pm</td>
<td>BREAK 12:45PM-2:00PM</td>
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<tr>
<td>2:00pm - 2:25pm</td>
<td>UPDATES IN VENOM ANAPHYLAXIS IN MAST CELL DISEASE (INCLUDING MCAS AND HAT)</td>
<td>Patrizia Bonadonna, MD</td>
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<tr>
<td>6:00pm - 7:00pm</td>
<td>SUPPORT GROUP - ADULTS WITH SM</td>
<td>Valerie Slee and Susan Jennings</td>
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<tr>
<td>7:00pm - 8:00pm</td>
<td>SUPPORT GROUP - YOUNG ADULTS (20-32)</td>
<td>Courtney Rabb and Jacob Hall</td>
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</tbody>
</table>

*Separate registration required. Link in Whova session or at tmsforacure.org.
MCAS EXPERT PANEL DISCUSSION AND Q&A
Sat. October 16th at 1:45pm - 3:45pm
Marla Barkoff, MD
Mariana Castells, MD, PhD
Anne Maitland, MD, PhD
Olga Pozdnyakova, MD, PhD
Anupama Ravi, MD

COMORBID CONDITION PANEL: UNTANGLING MCAS, EDS/CONNECTIVE TISSUE DISORDERS, DYSAUTONOMIA, AND IMMUNODEFICIENCIES
Sun. Oct. 17th at 11:00am - 12:30pm
Anne Maitland, MD, PhD
Clair Francomano, MD
Sarah Glover, DO, AGAF
Brent Goodman, MD
Jonathan J. Lyons, MD
Anne Maitland, MD, PhD
Cyndya A. Shibao, MD, MSCI, FAHA

AGRESSIVE DISEASE - PANEL DISCUSSION AND Q&A
Sun. October 17th at 1:45pm - 3:45pm
Jason Gotlib, MD, MS
Mark Heaney, MD
Deepti Radia
Srdan Versovsek, MD

DRAW MATTIE THE MAST CELL
Sat. October 16th at 12:00pm - 12:15 pm

SUPPORT GROUPS
PET LOVERS*
Sat. October 16th at 4:00pm - 5:00pm / Leaders: Valerie Slee and Jody Bachiman
*Separate registration required. Link in Whova session or at tmsforacure.org.

HAT*
Sun. October 17th at 4:00pm - 6:00pm / Leader: Jan Hempstead
*Separate registration required. Link in Whova session or at tmsforacure.org.

TEENS
Sun. October 17th at 7:00pm - 8:00pm / Leaders: Valerie Slee, Celeste Finnerty, and Janice Chiappone
*Separate registration required. Link in Whova session or at tmsforacure.org.
UPDATE ON HAT AND RELATIONSHIP TO MAST CELL DISEASE  
10:00am - 10:25am / Jonathan Lyons, MD

MCAS AND EDS - HYPERMOBILITY SPECTRUM DISORDER  
10:30am - 10:55am / Clair Francomano, MD

RELATIONSHIP BETWEEN MCAS AND DYSAUTONOMIA  
11:00am - 11:25am / Brent Goodman, MD

HYPERADRENERGIC POTS IN MCAS  
11:30am - 11:55am / Cyndya Shibao, MD, MSCI, FAHA

BREAK 12:00PM-1:30PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

HEREDITARY ALPHA TRYPTASEMIA  
1:30pm - 1:55pm / Sarah Glover, DO, AGAF

BREAK 2:00PM-3:00PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

BONE MARROW BIOPSIES IN PATIENTS WITH MCAS  
3:00pm - 3:25pm / Olga Pozdnyakova, MD, PhD

MCAS AND IMMUNODEFICIENCIES  
3:30pm - 3:55pm / Anne Maitland, MD, PhD

MANAGEMENT OF MCAS AND ENDOCRINE DISORDERS  
4:00pm - 4:25pm / Marla Barkoff, MD

SUPPORT GROUP - MEN'S*  
7:00pm - 8:00pm / Leader: Jacob Hall  
*Separate registration required. Link in Whova session or at tmsforacure.org.
## CONTROLLING GASTROINTESTINAL SYMPTOMS IN MAST CELL DISEASE

10:00am - 10:25am / Matthew Hamilton, MD

## TREATMENT FOR OSTEOPENIA AND OSTEOPOROSIS IN MASTOCYTOSIS & MCAS

10:25am - 10:55am / Giovanni Orsolini, MD

## COVID-19 IN PATIENTS WITH MAST CELL DISEASE

11:30am - 11:55am / Mariana Castells, MD, PhD

## BREAK 12:00PM-1:00PM

Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

## LONG COVID

1:00pm - 1:25pm / Theoharis Theoharides, MD, PhD

## AMERICAN INITIATIVES IN MAST CELL DISEASES (AIM) & TMS BOARD MEETING - CLOSED SESSION

2:00pm - 2:30pm

## IDENTIFYING NOVEL TARGETS TO INHIBIT MAST CELLS

2:30pm - 2:55pm / Mark Siracusa, PhD

## ADVANCES MAST CELL BIOLOGY THROUGH SINGLE-CELL RNA SEQUENCING

3:00pm - 3:25pm / Daniel Dwyer, PhD

## INTRO TO CLINICAL TRIALS AND UPDATES IN MASTOCYTOSIS

3:30pm - 4:15pm / Lauren Denton, MA, Blueprint Medicines & Cogent Bioscience

## SUPPORT GROUP - CAREGIVERS*

5:00pm - 6:00pm / Brian Hempstead

*Separate registration required. Link in Whova session or at tmsforacure.org.
HOW MAST CELL MEDIATORS CAN CAUSE ANXIETY, DEPRESSION AND BRAIN FOG AND OPTIONS FOR TREATMENT
10:00am – 10:25am / Theoharis Theoharides, MD, PhD

DYNAMIC NEURAL RETRAINING SYSTEM (DNRS): AN EFFECTIVE TOOL TO TREAT MAST CELL ACTIVATION
10:30am – 10:55am / Judy Tsafrir, MD

MANAGING NUTRITION WITH MAST CELL DISEASE
11:00am – 11:25am / Bonnie Nasar, RDN

BREAK 11:30AM-1:00PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

HOW TO TALK TO YOUR PHYSICIAN
1:00pm – 1:25pm / Valerie Slee, RN, BSN

THE POWER OF PATIENT ADVOCACY
1:30pm – 1:55pm / Shannon von Feldon, EveryLife Foundation

ANAPHYLAXIS - WHEN AND HOW TO TREAT
2:00pm – 2:30pm / Julie Wang, MD

ANAPHYLAXIS Q&A
3:00pm – 4:00pm / Matt Giannetti, MD

APPLYING FOR SOCIAL SECURITY DISABILITY
4:00pm – 4:45pm / Elevate Disability

BLUEPRINT MEDICINES COMMITMENT TO COMMUNITY
5:00pm – 5:25pm / Dave Dubinski & Paul Lim

BREAK 5:30PM-8:00PM
Visit the Community tab on Whova to network and meet 1:1 with others, join discussion boards, or participate in our photo contest.

CLOSING CEREMONY
8:00pm – 8:30pm
Join us to celebrate community, recognize International Mastocytosis & Mast Cell Disease Awareness Day, and announcement of community awards.
2021 Community Awards

Join us for our Closing Ceremony & Purple Tie Evening on October 20th at 8pm ET to recognize outstanding service in our community.

VOLUNTEER OF THE YEAR AWARD
TMS was founded upon volunteer service, and this year we are excited to have asked our community to nominate individuals for Volunteer of the Year. This award embodies our core value of patients first, recognizing volunteer service of individuals who went above and beyond to help the mast cell disease community. We are grateful to all those who volunteer to make our community stronger.

INNOVATION IN RESEARCH AWARD
The Innovation in Research award was created to recognize novel advances that will ultimately improve outcomes for patients with mast cell diseases. Thanks to the dedication of many scientists, much more is being discovered that gives insight into mechanisms underlying these diseases.
THE LIFETIME ACHIEVEMENT AWARD IN THE FIELD OF MAST CELL DISEASE RESEARCH & TREATMENT

The Lifetime Achievement Award in the Field of Mast Cell Disease Research was created to recognize an investigator who has dedicated his or her life to research into mast cell and/or other allergic diseases. Through the years, all of us at The Mast Cell Disease Society have been fortunate to have fostered strong relationships with many of the physicians who treat patients with mast cell diseases as well as those who do research into finding better methods for diagnosis and treatment. All of these great physicians have been a tremendous resource for those of us at TMS. We are so fortunate to have them to help and support us.

THE NORTON J. GREENBERGER, MD AWARD FOR CLINICAL EXCELLENCE

Dr. Norton J. Greenberger was a Senior Physician and Distinguished Clinician and Clinical Professor of Medicine at Brigham and Women’s Hospital Division of Gastroenterology. He had an extensive and impressive career that began at Yale and a fellowship in gastroenterology at Mass General Hospital in Boston and continued at various prestigious university hospitals throughout the Midwest, including 28 years at the University of Kansas, where he was the Chairman of the Department of Medicine. Dr. Greenberger passed away March 2020 of lymphoma. He was devoted to his wife Joan, three daughters and seven grandchildren.

Dr. Greenberger took care of many mast cell disease patients at the Center of Excellence for Mastocytosis in Boston. In addition to his mastocytosis patients, he treated over 100 Mast cell activation syndrome (MCAS) patients, an amazing number considering many mast cell disease experts will not treat patients with this diagnosis because of how much time they take. He was able to manage the complexities of mast cell disease with ease. He was innovative in approaching how to treat our relentless symptoms.

Our TMS Board voted to honor him with an award in his name immediately after his death. This Norton J. Greenberger Award for Clinical Excellence was created for a clinician who is devoted to their patients, is responsive to TMS when we call upon them for help with patient issues, who demonstrates clinical excellence in diagnosis and treatment, and is collaborative on research.
"So many challenges come with having MCD. Stay strong and never give up! We've got this. Sending good thoughts to all."

Judi Emmel, TMS

Special thanks to Dr. Leslie Oesterich!

Erica Horn

TMS Team & Our Doctors
With eyes of faith
Always Rejoice
In Wonders of Creation
Our Creator Give Us Courage
To Just Keep Smile-
With Unfailing Love-

Rosa Green


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You would no doubt agree that we are living through challenging times. Medical field are to be highly commended for your commitment to alleviate the pain and suffering.

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