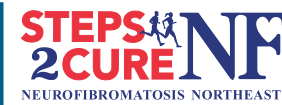


Thank You to Our Loyal Supporters

On May 24th Halley Elwell streamed a concert to benefit NF Northeast in conjunction with the release of her four-song EP (extended play) "The Last of What I Know." Music was always a clear path for Halley and now she is using her voice to change the narrative about neurofibromatosis so she can help others who live with it. "It's cathartic, it inspires me," the singer/songwriter says. "I get to write messages that inspire me and hopefully can inspire other people." To learn more about Halley and to hear her beautiful music visit halswellmusic.com



Halley Elwell



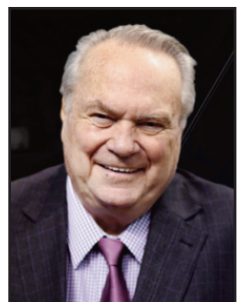
Steps2Cure NF was virtual this year, but that didn't make a difference to so many of our supporters. We are grateful to those who participated and shared their experiences with us.

We are sending A HUGE thank you to Amy and Tom Rodgers and their beautiful family for being our #1 fundraisers this year. With their help and the help of all participants we are able to continue

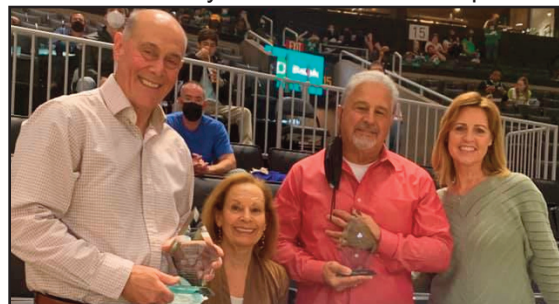


the fight to #EndNF. Also, congratulations to Mya Rodgers, shown with her parents and brother, for being an NFNE scholarship recipient this year!

Tommy Heinsohn - a dear friend to NFNE



Boston Celtics legend Tommy Heinsohn was the Honorary Chairperson of the annual NF Golf Tournament at the International for a span of 13 years. Tommy wasn't a celebrity chairperson in name only. Just like he did everything in life, he was 100% in our court. He was a spokesperson, fundraiser and a friend to all in our NF community. Tommy passed away in November and on May 9th the Celtics honored the icon with the inaugural "Tommy Heinsohn Day" - a day of on-air tributes hosted by the team and NBC Sports.



Tommy had worked closely with Paul Epstein and Steve Picardi, two dedicated volunteers from our NF community, and together they raised millions of dollars for NF

research and sponsorships for NF kids to attend Camp New Friends. It was a fitting and touching tribute that Paul and Steve were honored on "Tommy Heinsohn Day" with the prestigious **Heroes Among Us Award!** Pictured holding their awards are Paul and Steve with Trish Epstein and Susan Picardi.



May - NF Awareness Month

Governors around the country have signed proclamations to help create awareness of NF. Shown on left is the Hunsberger family with the proclamation from the Governor of Pennsylvania, and in the photo below the Callahan family with the Massachusetts proclamation.



9 Bedford Street
Burlington, MA 01803



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NF NEWS

NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

Volume 33, No. 1 Summer 2021

NF Northeast Announces new Executive Director

A message from Karen Peluso

Dear Friends in the NF Community,

Please join me in welcoming Sharon Klein, the new Executive Director of Neurofibromatosis Northeast. Following an extensive public search conducted in conjunction with TSNE Mission Works, the Board of Directors selected Sharon to fill the position that I have had the honor to hold for many years. I am retiring from the Executive Director position, and I will be assisting in the leadership transition.



Sharon Klein

With more than 15 years of non-profit fundraising experience, Sharon brings a focus and passion on finding cures for rare diseases. She has held numerous leadership roles in executive alignment and collaboration, fundraising, management, and patient advocacy and programs.

Sharon's career in the nonprofit world began right out of college, when she worked as a Program Coordinator at The Leukemia Society of America, now The Leukemia & Lymphoma Society (LLS). Working at what was then a grass roots organization and wearing many hats, Sharon quickly became well versed in relationship building, branding, and marketing. After serving in leadership roles in development at other organizations, including the Wang Theater, Sharon returned to LLS in 1999. Serving more than 12 years there, Sharon led philanthropy and patient initiatives for the Massachusetts and Rhode Island chapters, where she served first as the Director of Development and then later as Executive Director for both Chapters. Sharon is most proud of her accomplishments at LLS, where under her leadership, the Chapters raised more than \$6 million annually, to fund research and patient programs.

continued on page 4

EVENTS ARE BACK !!

Events serve many purposes: they help fuel our mission, they increase awareness of NF, and they bring our community together in a caring and supportive environment. Due to Covid-19 all events in 2020 were cancelled, but now as restrictions are being lifted we can get together again! Contact Diana Flahive at dflahive@nfnortheast.org for more information.



August 15th



10th Annual Bike Ride

September 11th



September 27th



at Worcester CC

October 4th

2021 Scholarship Recipients

A Message from the Chair of the Board of Directors

Executive Director Transition

On behalf of the Neurofibromatosis Northeast Board of Directors and Staff, I am pleased to announce the selection of Sharon Klein as our new Executive Director! The search for a new Executive Director has been a comprehensive, thoughtful and long process as the search last year was put on hold due to the pandemic. We are all in agreement that Sharon will be a great fit for our organization and brings years of experience which will help guide us and grow the organization to further fulfill our mission. As Karen mentioned in her message, Sharon has worked in the nonprofit sector for many years and recently worked for The Leukemia & Lymphoma Society as the Executive Director. She has also worked in other leadership positions and is passionate about rare diseases. Sharon officially started on June 28, 2021 and the Board, Karen, Diana and Anne have established onboarding and transition plans/activities. Karen has graciously agreed to stay on to assist with Sharon's transition so that it is as smooth as possible. Sharon lives in the greater Boston area with her husband and two children. Please join me in welcoming Sharon to our NF family! We look forward to you meeting her!



Lori Ryan, RN, MS, Chair

Also, please join me in thanking and recognizing Karen for being our beloved founder and long-standing Executive Director! Her tireless and dedicated work establishing and leading the organization has helped so many people affected by neurofibromatosis and allied disorders. Karen is a pioneer in this field and has helped facilitate NF research through our grant funding program and as a founding member of the NF Advocacy Coalition, to work with Congress to promote federal funding for NF. We are indebted to Karen's leadership and commitment to the NF community. She has strived to spread awareness to make neurofibromatosis a household word, and to support and educate families navigating the NF journey. Her work and vision have laid the foundation for NF Northeast's continued success in the future. I am sure that I echo many by saying that it has been an honor to work with Karen on the Board and as a volunteer for many years - I have learned so much from her and am grateful for her friendship, wisdom and passion. Although Karen is retiring from the Executive Director role, she will be an everlasting part of the NF community and organization which she, Bert and the early founders built in 1988!

As Karen always points out, "Patients and families are at the heart of NF Northeast's mission" and we are committed to continuing that legacy!

Lori Ryan

Our Vision: A world where the burden of neurofibromatosis does not exist.

Our Mission: To bring hope to those affected by neurofibromatosis and allied disorders. Patients and families are at the heart of NF Northeast's mission. We provide advocacy, support, and awareness while promoting research and enhanced clinical care.

NF Northeast Board of Directors

- | | |
|----------------------------|-------------------------|
| Lori Ryan, RN, MS, Chair | Robert Klouda |
| Robert Ryan, Treasurer | Andrés Lessing |
| Melissa Malerba, Secretary | John Manth |
| Patrick Callahan, Esq | John Shea |
| Alexandra Powers Cellucci | John Thomson, PhD |
| Justin Jordan, MD, MPH | Nicole Ullrich, MD, PhD |

NF Northeast Founders, Bert and Karen Peluso



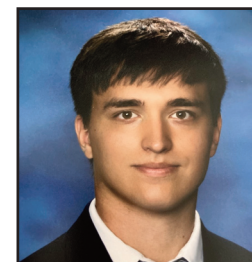
Caroline Burns from Ohio, will attend Pittsburgh Technical College as a freshman



Madeline Church from New Jersey, will attend Centenary University as a freshman



Mary Kate Cornetti from Pennsylvania, will attend Butler County Community College as a senior



Cameron Dannecker from New York, will attend Rochester Institute of Technology as a freshman



Abigail Dwyer from New York, will attend St. John Fisher College as a freshman



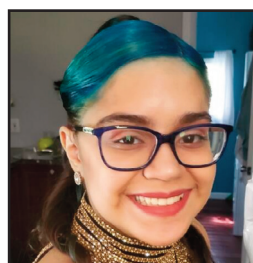
Jinya Fisher-LaPlante from Maine, will attend Case Western Reserve University as a freshman



Megan Gaffney from New Hampshire, will attend Sacred Heart University as a sophomore



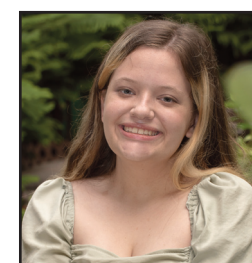
Chloe Kaplan from New Jersey, will attend Mount Holyoke College as a freshman



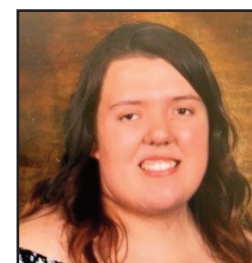
Genesis Lopez from Connecticut, will attend Naugatuck Valley Community College as a freshman



Teren Lover-Williams from Pennsylvania, will attend Cabrini University as a sophomore



Kallie McGonagle from Massachusetts, will attend Bridgewater State University as a freshman



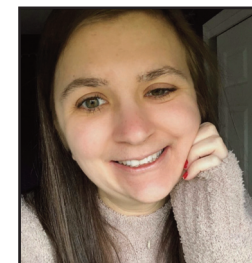
Kathryn Murdoch from New York, will attend St. John's University as a freshman



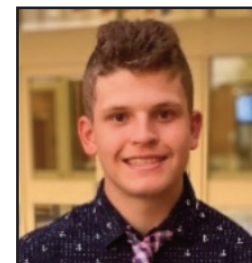
Sara Pavesi from New Jersey, will attend Rowan College South Jersey as a sophomore



Mya Rodgers from New York, will attend Siena College as a freshman



Madison Sassa from Pennsylvania, will attend Eastern Washington University as a sophomore



Andrew Voira from Connecticut, will attend Albertus Magnus College as a freshman

Welcoming Sharon Klein - continued from page 1

In 2018, Sharon decided to switch gears from working at a national nonprofit to a startup organization. Her curiosity about science led her to a senior leadership role at the Institute for Protein Innovation (IPI), a group focused on creating synthetic antibodies and creating new therapies for people with rare diseases.

I am personally very grateful that Sharon has returned to the rare disease space to take on the role as Executive Director at NF Northeast. She is a senior leader who is taking the helm at NF Northeast at a pivotal point in our 33 year history. I am confident that she possesses the passion and skills that are necessary to lead our organization into the future - a future without NF!

Karen Peluso

Contact Sharon at sklein@nfnortheast.org

A message from Sharon Klein
"I am looking forward to building lifelong partnerships and friendships throughout the NF community. My focus will be on accelerating funding mechanisms for new research initiatives in both basic and translational science. I will continue to reinforce NF awareness through patient advocacy, branding, and marketing. My goal is to inspire donors by supporting the best science in NF and related diseases, while providing hope for patients and families."

Anne Patterson - Director of Patient and Clinic Outreach

We are pleased to announce that Anne Patterson has been promoted to Director of Patient and Clinic Outreach for NF Northeast. In her prior role as Patient and Clinic Coordinator, Anne was responsible for the Tri State area. As Director her duties have been expanded to include the entire northeast where she will assist and support NF clinics and develop relationships with clinicians and physicians at targeted institutions. She will expand NF Northeast's patient and family support and continue to be a source of comfort and information for those who are newly diagnosed. Anne commented, "I will strive to build a sense of community for all those who are affected by NF - from individuals and families to NF clinicians and medical professionals." Please feel free to reach out to her with any questions at apatterson@nfnortheast.org.



Anne Patterson

College Scholarship Program

NF Northeast offers college scholarships for individuals who have neurofibromatosis and are continuing their education after high school. Grants are awarded annually to go towards college-related expenses, such as tuition/fees and books. Deadline for applications is April 15th. This program was established with funds raised at the Steps2Cure NF walks and has received generous support from East Cambridge Savings Bank.



The Guide for NF Patients and Caregivers Transitioning to Adult Care

Parents - what will happen when your child ages out of pediatric care? Will they transition into adult NF care? Or, drift away from NF specialists? The NF Collective has produced a great brochure and young adult webinar to help all concerned:

www.nfcollective.org/resources

Thank you! NF Northeast Annual Sponsors



NF Northeast Staff

Sharon Klein, Executive Director
 Diana Flahive, Director of Operations and Events

Anne Patterson, Director of Patient and Clinic Outreach
 Brooke O'Keefe, Marketing Intern