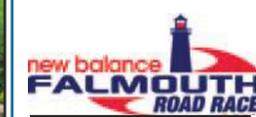


# Thank You to Our Loyal Supporters

## Did you know that NF Northeast raises 75% of its revenues at events?

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, and that was a good thing...until COVID-19! Now, everything is VIRTUAL but it hasn't stopped our NF community. They are determined to end NF!



**Nothing holds our volunteers back. Thank you everyone!!**



Let's all toast Team Riding for Roo led by **Michelle and Michael Donovan** (below) who have now raised \$201,963 in total for NF Northeast at Coast to the Cure Bike Rides for NF!



9 Bedford Street  
Burlington, MA 01803



return service requested



*We're Staying Strong in the Fight to End NF!*

# NF NEWS

NEUROFIBROMATOSIS NORTHEAST

Promoting Research, Awareness and Advocacy since 1988

Volume 32, No. 2

Fall 2020

## Addison's mother reflects on the "moments" of their NF journey

Written by Jillian Gould

Addison is our 3-year-old daughter diagnosed with NF1, currently going through chemotherapy for an Optic Pathway Glioma, that has grown rapidly and is threatening her vision.

Thinking back, there are many moments of our NF journey that are burned into my brain.

The first moment I googled "café-au-lait spots", after our NP briefly mentioned it at six weeks old, noting markings on Addison's skin. I remember sitting in disbelief after seeing pages of results on NF, thinking this couldn't possibly be part of Addison's story, could it?

The moment we were instructed that Addison should have an MRI to look for the cause of her drooping right eyelid.

The moment the neurologist came up to the recovery suite to say they had found bilateral Optic Pathway Gliomas. Our relief that we were just going to monitor the gliomas and our daughter would not need to go through any treatment at that time. Then we had a quiet year with no major issues, filled with normal follow ups, and hopes of future MRI's showing no further concerns.

Then came the moment when the other shoe dropped. At Addison's one-year follow-up MRI, her left optic glioma, which had been the smaller of the two, had grown considerably. It was causing a protrusion of her left eye that we had now been noticing for about a month and significant vision loss in that eye, which was new information for us.

All the moments started to blend together. The doctors moved with a new *continued inside*

### Neurocutaneous Syndrome Clinic Opens at Yale New Haven Hospital



Yale New Haven Hospital has announced the opening of a new multidisciplinary Neurocutaneous Syndrome Clinic (NCS) for patients aged 0 - 30 with NF1, NF2, and Tuberous Sclerosis. The clinic will be led by Dr. Asher Marks, MD, a pediatric neuro-oncologist with interest in the care of the NF population and experience with the use of cutting-edge therapeutics such as mTOR inhibitors, MEK inhibitors, and other standard cytotoxic chemotherapies. Congratulations to Frank Buono, PhD an advocate for the NF community and Yale faculty member whose vision and determination led to the clinic's formalization. For information or appointments, call the office of Dr. Marks at (203) 785-4640.



Addison

## A Message from the Chair of the Board of Directors

"We are all navigating this new normal together. As we lock arms virtually and try to help one another in the ways we can, our vast world suddenly feels a little smaller." (Michael Dell)



Lori Ryan, RN, MS

This year has brought extraordinary changes and pressures, but also opportunities. Let's highlight the accomplishment of having the first drug (Koselugo) approved by the FDA for neurofibromatosis, which will also help lead to interest in NF research and other approved drugs.

As you read the updates and heart-felt stories in the newsletter, please remember it's our community effort that will continue to fund the important research, advocacy program, educational support, scholarship and camp program, parent to parent program, etc.

Despite the many challenges the pandemic has brought, NF Northeast perseveres, adapts and continues to support and bring hope to those affected by neurofibromatosis and allied disorders.

As you know, the organization relies on events, corporate sponsors, and individual donors to fund our mission and due to the pandemic we had to cancel our in-person events this year, which has greatly impacted our revenue and staffing. We thank those who participated in our virtual events and continue to raise awareness and funds.

As we reflect on this year and plan for the year ahead, let's come together as a community to support each other and the great work of NF Northeast. It may be a new normal for all of us, however our vision of a world where the burden of neurofibromatosis does not exist will not change.

Wishing you a happy and healthy holiday season,

*Lori Ryan*

### 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
<i>Bert Peluso, Founder</i>	

### 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.*

### Our hope lies in clinical trials. Stay informed at [clinicaltrials.gov](http://clinicaltrials.gov).



This is Deniro Bruno with his mother Jessica. Deniro is on a Phase II study of Binimetinib a MEK inhibitor drug to shrink plexiform tumors.

Deniro has had 20.2% shrinkage of his tumor and minimal side effects. Deniro was featured in a video about the importance of advocacy for NF research that can be seen on the NFNE website. We will periodically keep you updated.

**INTUITT-NF2** stands for 'Innovative Trial for Understanding the Impact of Targeted Therapies in NF2.' In addition to schwannomas, NF2 patients can develop meningiomas and ependymomas. This new trial will allow for the simultaneous study of the various tumor types, rather than waiting for studies on one tumor type alone. The Principal Investigator of INTUITT NF2 is Scott Plotkin, MD, PhD from MGH and there are five additional participating centers.

*Addison continued* sense of urgency we hadn't seen before. Within a week of her MRI, we had signed consent forms for chemotherapy and Addison's port surgery, and her first chemo treatment was scheduled. The treatment would last 60 weeks. It didn't even sound like a real number. 14 months of weekly treatments and countless possible side effects, all on our 3-year-old spitfire daughter.

The moment we shared a cartoon video detailing what a brain tumor and chemotherapy are to Addison and her 5-year-old brother, Colin to prepare them for what she will be facing in the year ahead.

The moments have continued to pass in a blur. Her first treatment, followed by our first ER visit for fever, our first night of vomiting, the first sign of thinning hair etc.

Addison has remained our brave, spunky, strong daughter with an attitude for days, taking everything in stride as if she's done this all before. If there is one thing that we have learned, it is all about the moments. Not the hard, unexpected moments that I talked about above. Instead, the moments where we are all laughing together having a tickle fight or laughing at a funny thing that one of the kids say. The moment when Colin reads us a page out of a book for the first time or Addison comes in to wake us up in the morning wearing half her wardrobe all at once.



Graham, Colin, Jillian and Addison Gould

The moments where our kids tell us how much they love us for no reason at all. Although the hard NF moments may be burned into our brains, THESE are the moments I want us all to remember when we look back on this time. Well, let's be honest, these memories and a good MRI report!

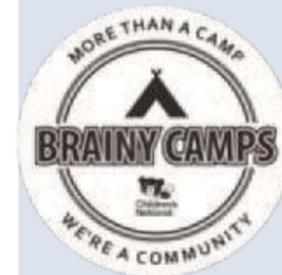
*Note: Since this was written, Jillian and her husband were diagnosed with COVID. They were both symptomatic. For 24 hours, until they could get both children tested, they parented them from inside their locked bedroom over FaceTime so as not to infect them. Both children tested positive and were asymptomatic, and then they could all isolate together. As Jillian said, "the panic and fear was real."*

### An invitation to youth and teens to attend Brainy Camps virtually this fall and winter

Covid-19 continues to impact the lives of everyone, and fortunately this summer, we saw how important it was for the Brainy Camps kids to stay connected to their friends. While they were disappointed not to have in-person camp, they were energized to see one another virtually and wholeheartedly participated in the activities. As a result, Sandra Cushner

Weinstein, PT LCSW-C and Susan Mehlman, Ph.D., the Brainy Camps co-facilitators are extending an invitation to other youth and teens with NF to attend camp virtually over the next few months. As they do at camp each summer, kids will meet in groups, giving them an outlet to talk about their experience with the pandemic and how their lives have changed. The kids will have a safe place to discuss their thoughts and feelings which can help them through these challenging times. They offer 3 groups to serve youth with NF. The groups are for adolescents, teens and transitional youth. Each group meets twice a month. There is no charge for these

groups. We hope you will encourage your children to join and meet with other kids with NF. If you are interested, contact Karen Peluso at [kpeluso@nfnortheast.org](mailto:kpeluso@nfnortheast.org) and she will assist you in the registration process.



## Helpful Resources for the NF Community During Tough Times



Meredith Chambers, M. Ed. is the Education Specialist on the Multidisciplinary Neurofibromatosis Team at Boston Children's Hospital. School looks very different this year with

many variations on different models, and Meredith has provided Zoom recordings to help families have the most successful school experience possible.

"Understanding the IEP" - A page by page look at the IEP and an explanation of each part of the document. With most IEP meetings being held remotely, it's a helpful guide.

"5 Components to Reading and a Reading Comprehension Checklist" - A quick overview of the components that make up reading and a useful comprehension checklist that can be used for an early fluent reader throughout high school. **Both recordings are available at [nfnortheast.org](http://nfnortheast.org).**

### NF Northeast College Scholarship Program



Applications will open in January, details are on the NFNE website.

### How you can support NF Northeast's programs

If you celebrate your birthday on Facebook, please think of having gifts go to NFNE. They are appreciated!



Do you have an idea for a fundraiser or virtual event to benefit NF? Please contact Diana Flahive at [dflahive@nfnortheast.org](mailto:dflahive@nfnortheast.org)

**amazonSmile**  
You shop. Amazon gives.  
please select  
NF Northeast  
as your charity

**MAKE A DONATION**

Hover your smart phone camera over the QR code  
Thank you!



**Committed to Curing NF** Every November for the past 10 years over 400 of Melissa and Mike Malerba's friends and family have packed Anthony's of Malden to raise funds for NF. This year, COVID was not going to stop the Malerba's. They planned a virtual event and their supporters



"showed up" as usual to generously support them and bring their grand total raised over the years to \$750,000! Congratulations to the Malerba's on another fabulous event!!

Are you an NF patient or family that is facing financial hardship? These organizations may be able to help.

**B THE DIFFERENCE**  
THE BRANDON MERRITT CHARITABLE FOUNDATION  
[bthedifference.org](http://bthedifference.org)

**SEVENTEEN22**  
FOUNDATION  
[seventeen22.org](http://seventeen22.org)

Have you put off an appointment with your NF specialist because of COVID? Do you have a new concern about your NF? Speak to your doctor about the possibility of a **Telehealth appointment**. Don't delay!

The AstraZeneca Access 360 program can help with affordability for drug costs for patients taking KOSELUGO (selumetinib) for NF plexiform tumors.

[MyAccess360.com](http://MyAccess360.com)



### NF Advocacy Days

will be the week of February 8th, and like everything else, they will look different this year. We will be virtually meeting with staff members, and we need your personal letters to your Senators and Representative now more than ever.



### Mya Rodgers "Shares the Love" with NF Northeast

Mya has been saving for college through CAP COM Federal Credit Union. Cap Com offered a "Share the Love" Sweepstakes and Mya was a winner! She won \$1,000 for herself and chose Neurofibromatosis Northeast as her favorite charity to receive \$1,000 from CAP COM. Thank you, Mya and CAP COM!

