

We've got a new logo, but our mission remains the same.

END NF

ANNOUNCING A NEW LOGO for the Children's Tumor Foundation

We are proud to introduce a new branding identity for the Children's Tumor Foundation. Research to end neurofibromatosis is the focus of what we do, and in order to enhance our ability to fulfill this mission, the Foundation's new logo more directly conveys this message. With an eye to increasing public awareness of NF, the new logo reflects our focus on research towards a cure.

We've always said that neurofibromatosis is hard to say, harder to live with. The new logo also helps focus on the acronym NF, bringing our message to a broader audience. We continue to focus on research, patient support and education, and the development of NF clinical centers. With the new logo, we also improve our public awareness efforts: to promote earlier and accurate diagnoses, to increase the public's understanding of NF, and to encourage support of this important cause.

We may have a new logo, but our mission remains the same... to End NF. To learn more about the Foundation's new brand identity, please visit: ctf.org/branding

A New Leader for the Children's Tumor Foundation

Annette Bakker, PhD

The Board of Directors of the Children's Tumor Foundation has elevated Chief Scientific Officer Annette Bakker to the position of President, succeeding outgoing President John W. Risner. A highly-regarded expert with vast experience in research and drug discovery, Dr. Bakker will be responsible for all facets of the Foundation's strategic initiatives and operations, including program development, fundraising, research, and public outreach. Along with her new responsibilities, she will also continue to serve as the Foundation's Chief Scientific Officer.



Since joining the Foundation in 2011, Dr. Bakker has led the expansion of the Foundation's research programs. The NF Preclinical Consortium has built a strong pipeline of promising compounds, which will be further enhanced by the NF Therapeutic Consortium, the Synodos research initiative has been established (see story below and on pages 4-5), an NF Biobank and NF Registry were launched, and an online NF data warehouse

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HISTORIC NEW INITIATIVE IN NEUROFIBROMATOSIS RESEARCH 'Dream Team' of Scientists to Collaborate in Unique NF Research Consortium

The Children's Tumor Foundation, the leading non-governmental organization dedicated to neurofibromatosis (NF) research, has announced an important new research collaboration called Synodos, a first-of-its-kind initiative dedicated to defeating the rare genetic disorder neurofibromatosis type 2 (NF2). This unique consortium brings

together a multidisciplinary team of scientists from twelve world-class labs at academic and medical centers of excellence who have pledged to work closely together – sharing information, datasets, results and more – at every step in research development, with the goal of speeding up the drug discovery process.

This group of talented researchers come from varying backgrounds – from basic science, to translational science, to clinicians – and have joined together in order to break down the barriers that have traditionally inhibited collaboration. Synodos represents a move from the traditional trial-and-error efforts of the past, and reflects

a desire from all involved to enable the most promising NF research, and to accelerate treatments.

Please turn to pages 4 and 5 for additional details on this important research initiative.



The Synodos 'Dream Team' gathers in Boston at Massachusetts General Hospital to launch work on the Synodos initiative.

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A New Leader for the Children's Tumor Foundation

Annette Bakker, PhD

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is soon to be live. A common thread among these initiatives is the steering of Foundation research goals from a pure funding model to one of partnership and collaboration.

"We are thrilled about the opportunities that Dr. Bakker's leadership will present to the organization and to the cause of ending NF," said Board Chair Stuart Match Suna. "Annette shares that same sense of passion and urgency about the work of our Foundation that all of those impacted by NF live with every day. We look forward to her bringing that sense of passion, urgency, and hope to her work leading this organization forward."

"I am truly honored and humbled to assume the leadership work of the Children's Tumor Foundation, and thank the Board and Foundation volunteers for their vote of confidence," said Annette Bakker, new President of the Foundation. "During my time here, I've worked with the best researchers in the field of NF, and I've spent time with NF patients young and old, and here's what all have in common: a desire to end as quickly as possible this disease that is just so destructive. Neurofibromatosis remains a mystery in so many ways, but we are committed to finding the solutions that will help those living with NF. My focus will be on seeking innovative breakthroughs in drug development, and effectively collaborating with all the stakeholders -- clinicians, researchers, academics, pharma, biotech, and other industry partners in the field of NF and related fields -- and last but not least, the patients."

Dr. Bakker holds a PhD in biochemistry from the University of Antwerp. Prior to the Children's Tumor Foundation, she was Oncology Head for Siena Biotech where she created the oncology program from the ground up and managed multiple oncology research initiatives in Europe and Asia. Her prior experiences include Oncology Group Leader at Janssen Pharmaceutica and postdoctoral fellowships at Yale University and La Salpetriere, Paris. Dr. Bakker's research has been internationally recognized by peer-reviewed papers, patents, and innovation awards.



She replaces outgoing President John Risner, who recently left the Children's Tumor Foundation after many years of service as its President and as a member of the Board of Directors. His leadership of the Foundation in fundraising, advocacy, and targeted research has resulted in the Foundation's funding of over 30 NF specific clinical trials and 80 drug compounds currently in existence, and an NF Clinic Network that currently treats over 10,000 patients per year in 44 clinics across the United States.

"On behalf of the entire CTF family, we are indebted to John for his passion and commitment to those affected by NF and for his years of service to the Children's Tumor Foundation," said Stuart Match Suna, CTF's Board Chair. "He has brought our organization to a level of professionalism to which other nonprofits can only aspire. John has ensured a smooth transition with a leader poised to take our urgent work to the next level."

"This Foundation is the best hope for the NF community to achieve our vision of ending NF once and for all," said John Risner, "While I am stepping down as President, I remain a committed member of the NF community and will be available to Annette as a volunteer in any way I can. Annette has proven herself to be a great leader in NF research and I am confident that she will be a great President."

FOUNDATION NEWS

SYNODOS' FOUNDING SUPPORTERS

The Children's Tumor Foundation is excited to announce Synodos' Founding Supporters: Mark and Tracy Galloway, and the Keller Research Fund. Both have generously agreed to support initial funding of this first-of-its-kind project.

Mark and Tracy Galloway have been long-time supporters of the Children's Tumor Foundation, and Tracy has served as a Member of the Foundation's Board of Directors since 2011. Their direction and spirit have been instrumental in building support of critical projects that have paved the way for Synodos.

The Keller Research Fund has been a transformative force in NF2 research. A portion of the bequest made by Cornelia Keller via the Fund will be directed to Synodos, and will serve as part of her lasting legacy in advancing treatments and cures for those living with NF2.

The long-time support of the Galloways and the Kellers has been critical to advancing NF2 research to this promising moment, and their commitments of \$300,000 each to Synodos are instrumental to the Foundation's ability to fund an expansive and ambitious project at the scale of



Synodos. The Foundation is very grateful for their support and excited about what the coming years will bring in the search for treatments and a cure.

If you are interested in making a major gift to Synodos, or similar NF1 and schwannomatosis projects, please contact Garrett Gleeson at ggleeson@ctf.org or 212.344.6633 ext. 8545. Your support can change the future for those battling NF.

UPCOMING AWARD APPLICATION DUE DATES:

Drug Discovery Initiative (DDI) Awards "A"

April 21, 2014

Clinical Research Awards (CRA)

July 15, 2014

Drug Discovery Initiative (DDI) Awards "B"

September 2, 2014

NF Clinic Stipend Awards

November 20, 2014

For more details visit www.ctf.org/research

UPCOMING EVENTS:

June 4-5, 2014: NF2 State of the Art Conference by Brigham and Women's Hospital and Massachusetts General Hospital, Boston, MA
www.phscpd.org/activities

June 6-8, 2014: NF Forum, Washington D.C.
www.ctf.org/nfforum

June 7-10, 2014: NF Conference, Washington, D.C.
www.ctf.org/nfconference

September 4-7, 2014: 16th European Neurofibromatosis Meeting, Barcelona
www.nfbarcelona2014.org

NF

It's Not Fair

Got your attention?

So should this: **Neurofibromatosis (NF)** affects one in 3,000 births. And it doesn't discriminate: NF strikes all populations, genders and ethnicities equally. With those odds, it's likely you have a connection to at least one person with this serious genetic disorder that causes tumors to grow anywhere in the body.

Don't let NF become just another forgettable acronym. After all, without a cure, those impacted by NF find it pretty tough to forget.

But there is hope, and you can make a difference. You can help us end NF. Together, we can give those affected by NF something to remember long from now - memories of the disorder they triumphantly beat "way back when."

Let's end NF - together. | CTF.org | 800.323.7938



Thank you to ICON International and Quicken Loans for their continued support of the Children's Tumor Foundation.

Did you see the full page ad that recently appeared in the Wall Street Journal?

Thank you to ICON International and Quicken Loans for their support of the Children's Tumor Foundation.

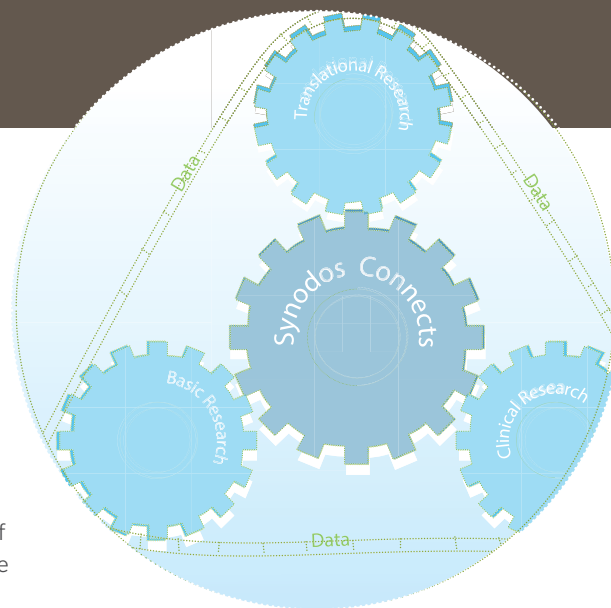
RESEARCH NEWS

SYNODOS *A Turning Point in NF2*

Developed and funded by the Children's Tumor Foundation, Synodos is a highly integrated, multidisciplinary consortium of scientists from varying backgrounds – from basic science, to translational science, to clinicians – who are working together to develop treatments for NF in a highly informed and highly collaborative manner. The consortium's comprehensive methodology is focused on real-time data sharing and understanding the underlying pathways of the disease – thereby going beyond the traditional trial-and-error efforts of the past – and proactively leveraging institutional collaboration and shared knowledge to lead to faster and better treatments.

The term synodos comes from the grouping of two ancient Greek words: *syn* and *odos*, which when combined mean 'to work together on the same path.' This spirit of likeminded purposefulness has brought together researchers from twelve world-class labs at academic and medical centers of excellence, and who are for the first time in NF research history sharing multidisciplinary datasets at every step of the drug discovery process in order to develop effective new breakthroughs that will end NF2.

Until now, NF2 research, and in fact, much



scientific research, is often done in a relatively siloed manner. The Synodos approach is modeled on the acclaimed 'Stand Up To Cancer' effort, in which interdisciplinary 'dream

“THE UNIQUE VALUE OF THIS CONSORTIUM IS IN ITS COLLABORATIVE AND MULTIDISCIPLINARY ACTIVITY, BRINGING RESEARCHERS TOGETHER IN A WAY SO AS TO UNDERSTAND NF2 IN ALL ITS CHARACTERISTICS AND MANIFESTATIONS.”

— **ANNETTE BAKKER, PHD**, *President and Chief Scientific Officer of the Children's Tumor Foundation*

WHAT WILL SYNODOS DELIVER?

- Multiple new and advanced cell and animal models to accelerate drug screening
- Real-time data sharing platform developed in partnership with Sage Bionetworks
- Detailed understanding of the research models in use across the NF2 field
- New target pathways
- Increased understanding of response and resistance to treatment
- Effective combination therapies
- New clinical trials for NF2
- Annual milestone reporting

teams' of scientists, clinicians, technicians and other experts work in concert, with the aim of finding solutions to the unique problems that affect patients. The Children's Tumor Foundation is bringing that successful model to NF2 research, addressing and overcoming a critical bottleneck in this research. We've identified the medical issues most faced by NF patients, requested proposals from the entire research community, and designed strategies that have a higher probability of finding solutions. Importantly, Synodos assembles the brightest minds in this field, and provides an

open computational platform for research collaboration free of bureaucratic obstacles and institutional competition. This is being done with the participation of Sage Bionetworks, a research institute that will 1) ensure data and knowledge are quickly disseminated throughout the consortium membership as they are produced and 2) create an online, publicly accessible record of the research performed by the consortium, allowing others to freely use the generated data for new purposes. Promisingly, this also has implications for disease research beyond neurofibromatosis.



“As an investor, you want to have a defined end goal, to know what you're investing in, to know what the risk is, and of course you want to know that there's going to be a return on that investment. And the return on an investment in Synodos is going to be that we will have answers to unresolved questions, and that we will have a treatment and a drug that is FDA approved.”

— **TRACY TULLOH GALLOWAY**, *Synodos Founding Supporter, Children's Tumor Foundation Board Member, and mother of a child with NF2*

WATCH THE VIDEO ONLINE
www.ctf.org/synodos



THE SYNODOS DREAM TEAM



Jaishri Blakeley, MD
Associate Professor of Neurology, Oncology, and Neurosurgery at Johns Hopkins University



James F. Gusella, PhD
*Bullard Professor of Neurogenetics, Harvard Medical School
Director, Center for Human Genetic Research, Massachusetts General Hospital*



Scott Plotkin, MD, PhD
Associate Professor of Neurology, Massachusetts General Hospital



Wade Clapp, MD
Chair of Pediatrics, Indiana University School of Medicine



“SYNODOS IS A SET OF PEOPLE WHO ARE TACKLING A DISEASE IN A WAY THAT IS DRAMATICALLY DIFFERENT FROM THE PAST, AND ALLOWS US TO HAVE INSIGHTS INTO NF THAT WE COULDN'T POSSIBLY HAVE OTHERWISE.”

— **STEPHEN FRIEND, MD, PhD** *President, Co-Founder and Director of Sage Bionetworks*

CENTERS OF EXCELLENCE

Synodos is a collaboration of researchers from twelve world-class labs at academic and medical centers of excellence, who are for the first time in NF research history sharing datasets in order to develop effective treatments for NF.

Jaishri Blakeley, MD

Associate Professor of Neurology, Oncology, and Neurosurgery at Johns Hopkins University and Director of the Johns Hopkins Comprehensive Neurofibromatosis Center (JHCNC).

Long-Sheng Chang, PhD

Investigator in the Center for Childhood Cancer and Blood Diseases, the Research Institute at Nationwide Children's Hospital and Professor in the Department of Pediatrics, The Ohio State University College of Medicine.

Wade Clapp, MD

Endowed Professor and Chair of Pediatrics at Indiana University School of Medicine

Cristina Fernandez-Valle, PhD

Professor, Burnett School of Biomedical Sciences, University of Central Florida

James Gusella, PhD

Bullard Professor of Neurogenetics, Massachusetts General Hospital and Harvard Medical School

Stephen Haggarty, PhD

Associate Professor of Neurology, Massachusetts General Hospital and Harvard Medical School

Gary Johnson, PhD

Professor and Chair of Pharmacology at the University of North Carolina

Helen Morrison, PhD

Molecular biologist and neuroscientist at Fritz-Lipmann-Institute in Jena, Germany

Scott Plotkin, MD, PhD

Associate Professor of Neurology, Massachusetts General Hospital and Harvard Medical School.

Vijaya Ramesh, PhD

Associate Professor of Neurology, Massachusetts General Hospital and Harvard Medical School.

Anat Stemmer-Rachamimov, MD

Associate Professor in Pathology, Massachusetts General Hospital and Harvard Medical School

D. Bradley Welling, MD, PhD

Chief of Otolaryngology, Massachusetts General Hospital, Chairman of Otolaryngology and Laryngology, Harvard Medical School

Racing4Research Speeds to Success in Daytona

Seven teams and 25 drivers raced to build NF awareness and raise funds for research into neurofibromatosis at the 2014 Rolex 24 at Daytona. All three Porsche 911 GT America teams racing in support of CTF persevered through a slew of endurance racing setbacks and, like the amazing NF Heroes they support, never gave up on accomplishing their goal of finishing America's premier 24-hour race.

This year's Rolex 24 campaign was an unprecedented effort anchored by Park Place Motorsports, Dempsey Racing, Compass 360 Racing, Ganassi Racing, and GMG Racing.

Joining the teams at Daytona were nearly 150 CTF families and supporters, including 30 NF Heroes. The children on hand were able to meet the drivers supporting CTF - including Patrick Lindsey, Mike Vess, Patrick Long, Patrick Dempsey, Kévin Estre, Connor De Phillippi, Jason Hart, Craig Stanton, and Dr. Jim Norman - at the Foundation's annual Family & Team Dinner held at the race track on Friday night. The fun and excitement continued pre-race as the families were treated to a private meet and greet session where the NF Heroes in attendance signed the flagship No. 73 Porsche which carried the names of 103 NF Heroes from across the United States and Canada.

Highlighting this year's campaign was the original artwork created by 20-year-old NF Hero and artist Jeffrey Owen Hanson. His bright and colorful painting inspired the livery on the No. 73 Children's Tumor Foundation/Racing4Research Park Place Motorsports Porsche 911 GT America as well as the one-of-a-kind helmet, donated by Bell Racing Helmets and painted by Troy Lee Designs, worn by actor and professional race car driver Patrick Dempsey.

The fundraising continues well past the completion of the historic race. In cooperation with Porsche Cars North America (PCNA), both Hanson's original painting





and Dempsey's helmet will be auctioned to benefit CTF at the Foundation's Annual Benefit Gala in New York City. And plans are currently under way with Porsche to produce a limited-edition 1/43-scale diecast collectible of the No. 73 "art car," which will be available directly from CTF and via Porsche sales channels including the Porsche Online Shop, Porsche Museum, and Porsche Shops in Zuffenhausen and Weissach, Germany.

If you are interested in joining the Racing4Research NF Hero team, please sign up today at www.racing4research.org.



Driver and "Grey's Anatomy" star Patrick Dempsey with NF Hero artist Jeffrey Hanson and his painting



LET'S WALK TOWARD AN END TO NF

Walk. Celebrate. Inspire

NF Walks are more than just a stroll in the park. These events often include refreshments, music, and fun activities like face-painting, arts & crafts, races for the kids, hula hoop contests, and raffles. Make memories with us in 2014 as we Walk towards an end to NF.

SIGN UP TODAY

- | | |
|------------------------|------------------------------|
| 5/10 Nashville, TN | 9/27 Central New Jersey |
| 5/10 Birmingham, AL | 10/4 Dallas, TX |
| 5/17 Kernersville, NC | 10/5 Los Angeles, CA |
| 5/17 Tulsa, OK | 10/5 Atlanta, GA |
| 5/18 Providence, RI | 11/8 Las Vegas, NV |
| 5/24 Staten Island, NY | 11/15 San Diego, CA |
| 6/8 Washington, DC | |
| 6/14 Greenville, SC | DATES TO BE ANNOUNCED |
| 6/21 Philadelphia, PA | Columbus, OH |
| 6/21 San Jose, CA | Iowa |
| 6/22 Cincinnati, OH | Jacksonville, FL |
| 6/28 Boston, MA | Jupiter, FL |
| 6/28 Chicago, IL | Kentucky |
| 7/27 Portland, OR | St. Louis, MO |
| 8/23 Utah | Mechanicsville, VA |
| 9/7 Denver, CO | Minneapolis, MN |
| 9/14 Rochester, NY | Monroe, MI |
| 9/13 Putnam, CT | |
| 9/20 Milwaukee, WI | |
| 9/21 Addison Oaks, MI | |

HELP US GET A WALK STARTED IN THE FOLLOWING AREAS

- | | |
|-------------|----------|
| Tampa, FL | Arkansas |
| Seattle, WA | Maryland |
| Arizona | |

Please email nfwalk@ctf.org



LACE UP IN 2014 WITH NF ENDURANCE

With the NFE Team, you get everything you'd want out of a great pair of shoes! Join us for upcoming events including:

- SacTown 10-miler (4/6)
- St. Anthony's Triathlon (4/26-27)
- Rock'n'Roll Portland Half Marathon (5/18)
- Spokane Summer Solstice 10K (6/20)
- Rock'n'Roll Chicago Half Marathon (7/20)
- Ironman Mont-Tremblant (8/17)
- Chicago Triathlon (8/23-24)
- Genworth Virginia 10-miler (9/26-27)
- Chicago Marathon (10/12)
- NYC Marathon (11/2)

...and more!!



STYLE

You'll look and feel like a VIP when you get access to premium sold-out races, benefits and discounts from our partners, and inspiration from our NF Heroes.

FLEXIBILITY

through our wide range of participation types. Select one of our Premier Events, Community Events, Kids Events...or Choose Your Own race!!

SUPPORT

to reach all your training and fundraising goals, through personalized coaching and one-on-one assistance from staff and volunteers to create your fundraising plan.

IT'S OKAY IF YOU DON'T RUN, BIKE, OR SWIM

} There are other ways to get involved with the NF Endurance Team!

1) BECOME AN NF ENDURANCE TEAM HERO

You or your child can inspire our athletes to train harder and fundraise more! Through our Adopt-a-Hero Program, each of our athletes is paired with one of our NF Heroes who write letters, send photos or videos, and motivate the NFE Team members toward the finish line. Learn more and become one of our NF Heroes by contacting Lauren at lwalsh@ctf.org.

2) JOIN OR CREATE A VOLUNTEER COMMITTEE

Want to see the NFE Team in your local race? We need YOUR help! We rely on dedicated volunteers to help us organize NFE events across the country. You can help our program grow by starting a volunteer committee for a Community or Kids event in your town or school. Our staff provides the structure, guidance, and support to help you succeed! Contact Angela at aauzston@ctf.org for more information or to find an existing committee near you.

CUPID'S UNDIE RUN

Cupid's Undie Run Smashes Fundraising Record

CHERUBS 'FUNDRAISED THEIR PANTS OFF' TO RAISE OVER \$2.7 MILLION FOR THE CHILDREN'S TUMOR FOUNDATION

On February 15, 2014, 16,000 scantily clad runners, in 27 cities across the United States and three cities in Australia, participated in the Children's Tumor Foundation's newest fundraising program, Cupid's Undie Run. Sponsored by MeUndies, the event involves running a mile in underwear, outside, over Valentine's Day weekend to raise funds and awareness for neurofibromatosis (NF), a disorder that can cause tumors to grow on nerves throughout the body and affects one in every 3,000 people. This year, the charitable cherubs raised well over \$2.7 million, more than double what they brought in last year!

The idea for Cupid's Undie Run was born in 2009 to help a friend in need. Chad Leathers and his best friend, Brendan Hanrahan, were sitting next to Chad's brother Drew's hospital bed at Johns Hopkins. Drew, who had been diagnosed with NF

four years earlier, had been in the hospital for over 180 days, become a quadriplegic, and was suffering excruciating pain daily. Wanting to help somehow, they began sharing ideas on how to raise funds for NF research.

Chad and Brendan were both avid runners so they settled on a fundraising race, but they wanted it to be unique. "I thought, there are a lot of runs out there, but none in underwear during the winter," said Brendan, "That ought to get people's attention." Since they not only wanted to raise funds but also NF awareness, Chad agreed saying, "Nothing draws a crowd like a crowd, and nothing draws a big crowd like a crowd in their underwear. Let's do it!"

Chad and Brendan were joined by friends Bobby Gill and



"WHAT STARTED AS A SMALL EVENT TO HELP A FRIEND HAS GROWN INTO AN INTERNATIONAL EFFORT THAT INCLUDES THE SUPPORT OF THE ENTIRE NF COMMUNITY AND BEYOND."



Tamara Forsy in creating the first Cupid's Undie Run (CUR) in Washington, D.C. in February 2010. That year, more than 650 runners participated and raised over \$10,000. Four short years later, CUR has attracted 25 times the amount of participants and increased their fundraising total 200 fold.

"What started as a small event to help a friend has grown into an international effort that includes the support of the entire NF community and beyond," said Bobby, "It's amazing, a majority of our race organizers, who are all volunteers, and our participants are completely unaffected by NF; just good people wanting to have fun while benefitting a great cause."

New York City Cupid's Undie Run Race Co-Director Julie Pantoliano agreed saying that participants were inspired by those that live with NF. "The people that we're running for have an incurable disease with awful manifestations, and are often in pain every day," said Julie, "With that in mind, we can bear running in the cold in our skivvies for a little bit."



For more information about Cupid's Undie Run or to make a donation, please visit WWW.CUPIDSUNDIERUN.COM.

MEET THE STAFF

Angela Dumadag

HOMETOWN: Jersey City, NJ

CURRENT TOWN: New York, NY –
the Lower East Side

EDUCATION: B.S. in English Education from
New York University, May 1999

WORK WITH THE FOUNDATION: I am the
New York Team Manager for NF Endurance,
and my job is to build the NF Endurance
participant and volunteer base in and around
metro New York City. My primary events are
the NYC Half Marathon, the New York City
Marathon, and a few smaller local races. I also
am growing and managing our Volunteer
Committees for NYC and Long Island, NY.

FAVORITE EXPERIENCE WITH THE FOUNDATION:

Volunteering at
the Cupid's Undie
Run NYC last
month – to see
nearly 1,000
people, most
of whom had
never heard of the
Children's Tumor
Foundation or NF,
take off their clothes and help raise close to
\$3 million dollars was quite an experience!

FAVORITE HOBBY: I love combining travel with
triathlon and marathon races. I also enjoy meals,
craft beer, and wine with friends!



MEET THE BOARD

Matthew Hay



HOMETOWN: Newburgh, IN

CURRENT TOWN: Munster, IN

EDUCATION: BS in Marketing and an MBA, both
from Indiana University

WORK WITH THE FOUNDATION: In my first year on the Board of Directors, it
seems my biggest task has been to listen. The Foundation has so many exciting
things happening at any given moment, from funding dozens of cutting-edge
clinical trials to running in undies, that there is a lot to learn. As a member of the
Public Education and Awareness committee, I try to bring a balance of profes-
sional experience based on 15 years in marketing and personal experience based
on 20 years of living with NF2.

FAVORITE EXPERIENCE WITH THE FOUNDATION: There have been a lot of NF
Endurance event finish lines crossed that were exciting for me, but one non-race
moment with the Foundation really stands out. Last summer at the NF Forum, I
found myself in a dinner conversation with a number of individuals I had not yet
gotten to know. I soon learned that these wonderful people were Dr. Marco
Giovannini, Dr. William Slattery, and Dr. Gareth Evans, some of the leading minds,
worldwide, in NF research and treatment. These doctors were a part of a larger
group that were brought together that weekend by the Foundation to share ideas,
studies, and progress in their work with neurofibromatosis. As they asked me about
my life with NF and shared more of their own personal experiences, the humanity
and passion they showed for what they do was inspiring. I've always thought of NF
as an endurance event of its own and after an evening with medical professionals like
these, I was convinced that the work that CTF and the NF community is doing will
lead to a cure. That's the finish line that we all want to cross.

FAVORITE HOBBY: With three kids ages 5-7, much of the time my wife (a modern-
day Wonder Woman, minus the invisible jet) and I spend outside of work is at a
gym/field/court watching whatever activity is in season for them. When not doing
"dad things," I can probably be found training with the NF Endurance Team, fishing,
watching Hoosier basketball, or sampling some of the Midwest's great microbrews.

JOIN US FOR THE NF FORUM

The Sixth Annual NF Forum will be held
June 6-8, 2014 in Washington, D.C. The NF
Forum is a weekend-long patient and fam-
ily support meeting where attendees learn
about the latest medical advancements
in neurofibromatosis research and about
resources provided by CTF.

Some topics covered this year will include:

- Social difficulties and learning challenges
faced by children with NF
- Functioning in a healthy way at school
and in extracurricular activities

- Psychological issues that affect personal
development of those with NF

Activities available to attendees of the 2014 NF Forum:

- A night tour of Washington, D.C.'s
monuments
- A joint dinner with attendees of the NF
Conference, (held in conjunction with the
NF Forum this year), featuring a keynote
address by Dr. Francis Collins, MD, PhD,
Director of the National Institutes of Health
- An NF Walk through the streets of the
nation's capital

For more information and to register,
please visit www.ctf.org/nfforum!



REGIONAL NEWS

Great Events from Across the NF Community

The Foundation has a presence in nearly all 50 states and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children's Tumor Foundation Chapter in your area by visiting www.ctf.org/communityrelations.



CALIFORNIA

During the fall of 2013, Laurel Hall School in North Hollywood, CA collected chapel offerings for the Children's Tumor Foundation on behalf of 7th grade NF Hero Blake Robinson.

NEW COMMUNITY RELATIONS SECTION ON WEBSITE

Announcing a new and easier way to get involved with the NF community in your area: the all-new Community Relations section of the Children's Tumor Foundation's website. Please visit www.ctf.org/communityrelations, click on your state, and easily find local Foundation contacts, events, doctors, NF families, and other information for your region. The pages will be updated on a regular basis, so be sure to visit often.



UTAH

The Utah Chapter hosted their annual NF Symposium on October 26, 2013 in Salt Lake City at Shriners Hospital For Children. More than 75 people attended this informative event and enjoyed interacting with other NF families from the area.



IDAHO

The Children's Tumor Foundation is thrilled to welcome its new chapter in Idaho! Previously known as NF Idaho, the organization joined CTF in December 2013 and brings an enthusiastic and dedicated group of people to help raise NF awareness and funds for research throughout the state. We look forward to a wonderful collaboration!

CALIFORNIA

The California Chapter hosted an Elks Mega Golf Tournament in honor of NF Hero Dakota Anderson on September 28, 2013 in Atwater, CA and raised money for the Racing4Research program.



TEXAS

The Texas Chapter held a garage sale September 26-28, 2013 to help raise money for Team Connor's Crew and the Dallas NF Walk. This was their second event and both were very successful. Special thank you to Tammy Benson-O'Brien and her family.



REGIONAL NEWS



LOUISIANA

CTF's Louisiana Chapter held an Educational Symposium on February 1, 2014 at Children's Hospital in New Orleans, Louisiana. All who participated enjoyed learning and sharing about NF while attending seminars by Dr. Bruce Korf, Dr. Karen Weissbecker, and Dr. Michael Marble, among others. In addition to the Educational Symposium, a simultaneous Children's Symposium was held in another area of the hospital, culminating in an Art Project Display at the end of the day.



MASSACHUSETTS

May 10, 2014 - The annual Molly's Royal Faire in Amesbury, Massachusetts. Games, food, and fun for the whole family!

COLORADO

The Colorado Chapter hosted an NF Medical Symposium on October 20, 2013 at Children's Hospital Colorado in Aurora, CO. This educational event included seminars on different topics pertinent to NF and gave the families in attendance the opportunity to interact with specialists in the field of neurofibromatosis.



CALIFORNIA

The Valencia, CA branch of Southern California Edison (SCE) invited Children's Tumor Foundation Employees Kelly Mills and Kim Robinson to give a presentation on NF at the Southern California Edison's Employee Contributions Rally on Oct 24, 2013. In addition, Kelly and Kim were presented with a donation of \$4,000 from the generous employees of SCE. A very special thank you to everyone at Southern California Edison - Valencia District.



NEVADA

On October 5, 2013, the Nevada Chapter hosted a kickoff event at E-String's restaurant in Henderson, NV to encourage fundraising efforts for the 2014 Las Vegas NF Walk.



NEW JERSEY

March 29, 2014 - The eighth annual NF Casino Night at the Sheraton in Mahwah, New Jersey.



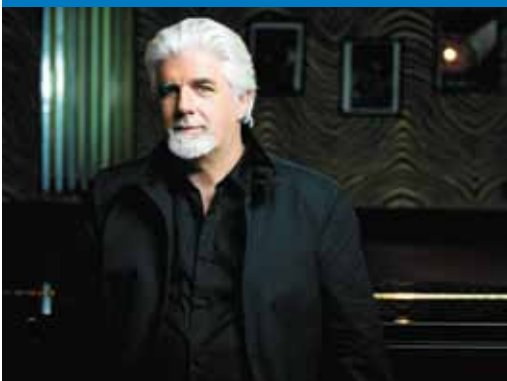
ARKANSAS

September 11, 2014 - The Red Carpet for Research "Dancing with Our Stars" gala event in Little Rock, Arkansas.



MASSACHUSETTS

On January 16, 2014 the Children's Tumor Foundation hosted a "Paint Nite" event at the Hingham Beer Works in Hingham, MA to raise funds for the Boston Cupid's Undie Run. It was an evening of fun, wine, and painting as Artist Monica helped participants create masterpieces.



TENNESSEE

May 8, 2014 - A Michael McDonald concert at the Franklin Theatre in Nashville, Tennessee, including the auction of a signed guitar from Keith Urban; all proceeds will benefit the Children's Tumor Foundation.

STORIES OF NF: *Rhianna Curotto*



My name is Rhianna Curotto, I am 26, and I was diagnosed with NF2 five and a half years ago. Getting a phone call saying, “You have two brain tumors” was probably the scariest moment of my life.

The first thoughts running through my head were, “I am going to die” and “What do I do???” It wasn’t until I met my NF specialist that my mindset changed from negative to neutral/positive. I see Dr. Plotkin in Boston, MA and he has been my savior. Although there are many unknowns with neurofibromatosis, he always answers my questions directly and I never doubt him.

Further testing indicated that I also have a tumor on my spine, some neurofibromas, and facial weakness. For a while my doctor advised that we “watch and wait,” but my brain tumors were growing like weeds and becoming frightening! I was having very bad migraines and lots of dizziness. I won’t list the tumor’s measurements because I only know them in volume, and those numbers are scary to people who think of them two dimensionally, but let’s just say I was at the point where a decision had to be made

“It may seem like you’re all alone but you are not.”

as to what path I would take. Surgery? Chemotherapy? Still watch and wait? I was terrified to have to make such a life-changing decision, but I chose chemotherapy. I have been on and off Avastin (bevacizumab) for over two and a half years and it is doing a great job of shrinking the brain tumors. Of course pumping poison into your body is going to have some side effects, but to me it is worth it.

Because of NF and the chemo negatively affecting my reproductive system, my husband and I chose to adopt. I am thrilled to announce that we currently have a little, teeny, tiny, baby boy with us! He is three months old and we couldn’t be happier! We are waiting for everything to be finalized, and the waiting is difficult, but in the meantime we are enjoying every day with our son. My main concern after being diagnosed was whether I would be able to live a normal life. Well guess what, I am living a normal life! I am married and I have a child! I know that all cases are different so I consider myself lucky.

I am currently the President of the Children’s Tumor Foundation’s Chapter in Connecticut and I love every minute of it. Our second annual NF Walk in Putnam, CT will take place on Saturday, September 13th and we hope to raise even more than the \$21,000 we brought in last year!

So keep on keeping on my NF friends! It may seem like you’re all alone but you are not. Hold your head up, rally on, and live your life in your own unique way. As Dr. Seuss once said, “Today you are You, that is truer than true. There is no one alive who is Youer than You.”

NF News is the official publication of the Children’s Tumor Foundation and is published quarterly. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to the editor (listed below).

The Children’s Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to finding effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF can cause tumors to grow on nerves throughout the body and may lead to blindness, bone abnormalities, cancer, deafness, disfigurement, learning disabilities, and excruciating and disabling pain. NF affects one in every 3,000 people, more than cystic fibrosis, Duchenne muscular dystrophy, and Huntington’s disease combined. The Children’s Tumor Foundation funds critical research into neurofibromatosis. In addition to benefiting those who live with NF, this research is shedding new light on several forms of cancer, brain tumors, bone abnormalities, and learning disabilities, ultimately benefiting the broader community. For more information, please visit www.ctf.org.

Editor

Mary Vetting, mvetting@ctf.org

FOUNDATION STAFF

Annette Bakker, PhD, President and Chief Scientific Officer

Research and Medical Programs

Pamela Knight, Clinical Research Manager

Salvatore La Rosa, PhD, Director of Research and Development

Patrice Pancza, Research Program Director

Sarah Rosenberg, Program Assistant

Kimberly Scobie, PhD, Scientist

Development and Volunteer Relations

John Heropoulos, Senior Vice President

Traceann Adams, Program Director, NF Walk

Angela Auzston, NF Endurance Mgr, Community & Youth Events

Jill Beck, Program Director, Racing4Research

Jessica Beckerman, NF Walk Coordinator

Carolyn Castellano, Program Director, Major Events

Chrissie Connors, NF Walk Coordinator

Emily Crabtree, Program Director, NF Endurance

Angela Dumadag, NF Endurance Manager, New York

Garrett Gleeson, Program Director, Major Gifts

Ben Leathers, Cupid’s Undie Run, Apparel Logistics & Reporting

Chad Leathers, Program Director, Cupid’s Undie Run

Alissa Marks, NF Endurance Manager, Marketing

Kelly Mills, Community Relations Regional Manager

Sarah Morley, Cupid’s Undie Run National Events Coordinator

Marissa Moscatello, Community Relations Coordinator

Julie Pantoliano, Community Relations Coordinator

Kristine Poirier, Community Relations Coordinator

Lauren Walsh, NF Endurance Manager, Chicago

Public Education and Patient Advocacy

Simon Vukelj, Communications Director

Mary Vetting, Communications Associate

Finance and Administration

Judi Swartout, Chief Financial Officer

Mohamed Amin, Database Assistant

Monique Boucher, Database Supervisor

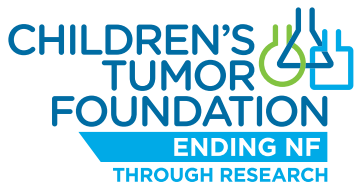
Sarah Bourne, Accountant

Danielle Meyer, Technical Support, National Programs

Rosa Amelia Perez, Project Administrator

Sean Thompson, Director of Technology

Vanessa Younger, Program Assistant



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120 Wall Street, 16th Floor
New York, NY 10005
800-323-7938
www.ctf.org

Registration Open!

NF CONFERENCE

June 7-10, 2014
Omni Shoreham,
Washington,
D.C.

www.ctf.org/nfconference

NF FORUM

June 6-8, 2014
Omni Shoreham,
Washington,
D.C.

www.ctf.org/nfforum

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AND YOU CAN HELP **END NF**

MICHIE O'DAY
Honorary Children's
Tumor Foundation
Board Member
Portland, ME
Lives with NF2

I joined the registry because...

"THERE IS POWER IN NUMBERS."

www.nfregistry.org