14 Stories

a guide for patients and families
living with neurofibromatosis

FOREWORD AND ACKNOWLEDGMENTS

From the moment our son Drake was diagnosed with neurofibromatosis (NF), my husband Steve and I set out to find a definitive source to help us better understand the disease and what lay ahead for our son. That task was daunting and frustrating. It seemed few people had ever heard of NF, and the information we did find was severe or incomplete.

We wanted answers. We wanted examples of what life with NF would mean for Drake, and we wanted to know how we could help him. It was these frustrations that inspired this book, which we hope will help other NF families who seek direction and support.

Our second of three children, Drake can be found most often in an action hero costume, soaring his action hero "guys" in the air for hours. To date, he is one of the lucky ones. Though he has a Lisch nodule on his eye and about 1,000 café au lait spots and freckling, he is mildly affected. He has overcome many of his digestive, fine motor and gross motor issues and can run the T-ball bases with a snail-paced fury that ignites the stands when he finally reaches home plate.

What will Drake's story be in three months, in 10 years? That is the worry NF patients and parents carry in their hearts every day. Though a diagnosis of neurofibromatosis may seem a heavy weight to bear and comes with an unpredictable future, it is important to know that great strides are being made in NF research and that NF patients have the full support of the Texas Neurofibromatosis Foundation, which helps over 1,400 NF families each year.

And although NF is not a welcome diagnosis, some of our family's most important life lessons have come with it. We have learned to focus on what matters most and are working to be our son's biggest advocate – pushing forward to find the doctors and therapists who are equally passionate about making a difference for NF patients.

We may not have taken that path if it were not for our family, friends, doctors, and the Texas Neurofibromatosis Foundation. We are especially grateful to our families, to Beth and Frank Cory, who have shown us the way with optimism and compassion, and to Dr. James Mahoney, who is as much our counselor and cheerleader as he is our trusted physician. He has never settled for status quo and has made significant improvements in Drake's life because of his dedication to our son's health.

Equally important are the people who generously donated their time and talents to produce this book. The stories of 14 NF families were beautifully captured through the photography of Mark Mahan and the words and design of Jason Niebaum and Chris Cima at TM Advertising. Our most heartfelt appreciation also goes to Cindy Hahn at the foundation and the NF families who shared their stories in this book for the benefit and comfort of others. Thank you.

We wish every NF family the support and resolve to become an advocate for yourself or your loved one in the fight against NF and hope this book provides a place to start.

Suzanne and Steve Miller

INTRODUCTION

If you're reading this, chances are you or somebody you know has just found out they have a disease called neurofibromatosis. And though it will take some time for the idea to sink in, you probably have a million questions. Like how did this happen? Will I get sick? What can I do about it? And how do you even pronounce neurofibromatosis?

It's okay to have questions. After all, this whole experience may be a little scary. But the scariest part by far is not having answers. And that's where *14 Stories* begins.

This booklet was designed to be a starting place for new patients with neurofibromatosis and their families. An honest resource that addresses many of the concerns you might have and also provides medical and support group contacts.

In the pages ahead, you'll find lots of up-to-date information about NF and, in the process, meet 14 other wonderful, brave patients who are going through some of the same things you are. You'll see how they're dealing with the disease and what you can do to deal with NF as well.

WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (nu-ro-fi-bro-ma-tóe-sis), or NF, is a little-known disease that primarily affects the growth of neural (nerve) cells. This causes tumors to grow on nerves and produce other abnormalities such as skin changes and deformities. But NF may affect almost any organ of the body. It occurs equally in both men and women, in all races and ethnic groups. Because the symptoms are varied, uncertain, and progressive, NF is hard to define or picture.

There are two types of neurofibromatosis – NF1 and NF2. NF1 is the more common type, occurring in about one in 4,000 individuals worldwide. NF2 is less so, affecting about one in 40,000 persons. NF is, in fact, the most common neurological disorder caused by a single gene. It affects more people than most forms of muscular dystrophy, and it's more common than cystic fibrosis. At this time, there is no cure, no treatment, and no known prevention for the disease.

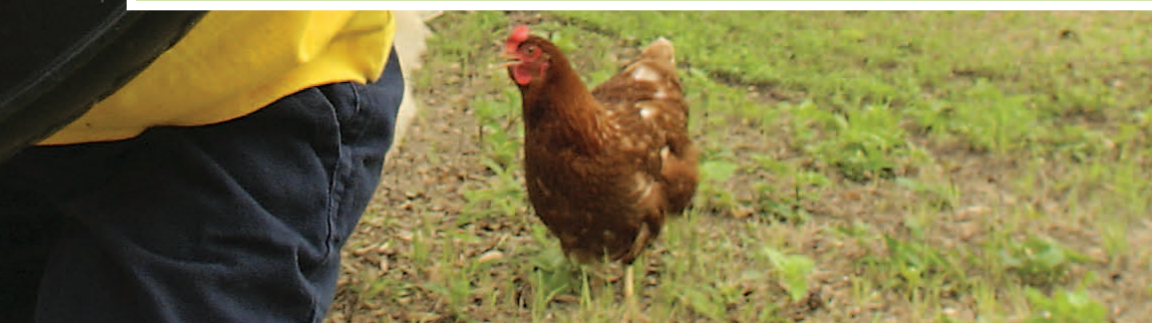
WHAT CAUSES NF?

NF is a genetic disorder, which means that it is caused by an abnormal gene in the body. NF1 and NF2, however, are completely different because the genes responsible for each are located on different chromosomes. The NF1 gene is located on chromosome 17, and the NF2 gene is on chromosome 22. People have 46 chromosomes, receiving 23 chromosomes from each parent. Chromosomes carry genes that determine an individual's characteristics, development, and health.

There are two ways a child can be born with NF. The gene that causes NF can be inherited from one of the parents, or it can be a spontaneous mutation where a gene became defective before birth. Neurofibromatosis is a genetically dominant disorder, which means that, if either parent has the defective gene, each child born to that parent has a 50 percent chance of inheriting the defective gene.


FLEXIBLE FLYER

Robert Ferris has NF1. Shortly after he was born, Robert developed a tumor on his face near his right cheek. Because the tumor isn't painful or critical, Robert's doctors will wait until he's older before they consider removing it. And though he must be careful to protect his face, Robert hasn't let NF interfere with his love of swimming, fishing, hunting, and his favorite thing to do – just being a kid.



With NF1, it's not uncommon for patients to develop light-brown markings on their skin called "café au lait" spots. Whitney began noticing these spots on her torso at age 5, a characteristic that helped doctors diagnose her. She has a terrific outlook on living with NF and is always busy with one activity or another. In fact, between school, volleyball, and horseback riding, Whitney (shown with older sister Courtney, seated) hardly ever seems to take a break.

ABOUT NF1

NF1 is the more common form of neurofibromatosis. It is sometimes referred to as "peripheral neurofibromatosis," or Von Recklinghausen's Disease. There are many affected people who inherit NF1, but between 30 and 50 percent of new cases are spontaneous.

Those with NF1 typically have café au lait spots – light-brown circular markings on the skin and freckling under the arm or in the groin area. Lisch nodules, which are brownish red spots in the iris of the eye, will sometimes accompany these spots. Tumors can form in different parts of the body with NF1. These can be small tumors called neurofibromas and can appear on or below the surface of the skin. There can also be tumors or growths involving the skin and deeper tissue, including the nerves, called plexiform neurofibromas. Not often, but occasionally, plexiform neurofibromas can transform into a dangerous cancer known as neurofibrosarcoma.

Molly Johnson, a.k.a. the “Princess of Paint,” lives with something called a plexiform neurofibroma, a nodule-like tumor that grows under the skin and affects many nerves. It isn’t contagious, but changes in size must be monitored constantly. Any growth or movement of a tumor can potentially become cancerous, so every three months, Molly and her mom make sure to visit her physician to help keep an eye on things.

Children with NF1 often have learning disabilities and can develop physical growth problems. They may be shorter or have a slightly larger head than an average person. NF1 can also affect the way bones grow. A few people experience shrinkage of a bone, called atrophy, or bending or fracture of a long bone that will not heal, called pseudarthrosis. Scoliosis, which is curvature of the spine, is also common in people with NF1.

NF1 can also affect the brain. In a small number of people, NF1 can cause brain tumors. Nerves to the eye can be abnormally large, which indicates an optic glioma – a growth on the nerve to the eye. Frequently on brain scans doctors find bright spots, not to be confused with brain tumors, that are simply another indicator that a person has NF.

NF1 can affect almost any organ in the body, though many people have only a few difficulties. In some cases, patients with NF1 may have only café au lait spots and neurofibromas, but others may experience more difficult problems. NF1 is unpredictable – no two people are affected the same way, not even within the same family, and no doctor can tell you in advance what will happen to you or another person with NF.

WHEN DO SYMPTOMS APPEAR WITH NF1?

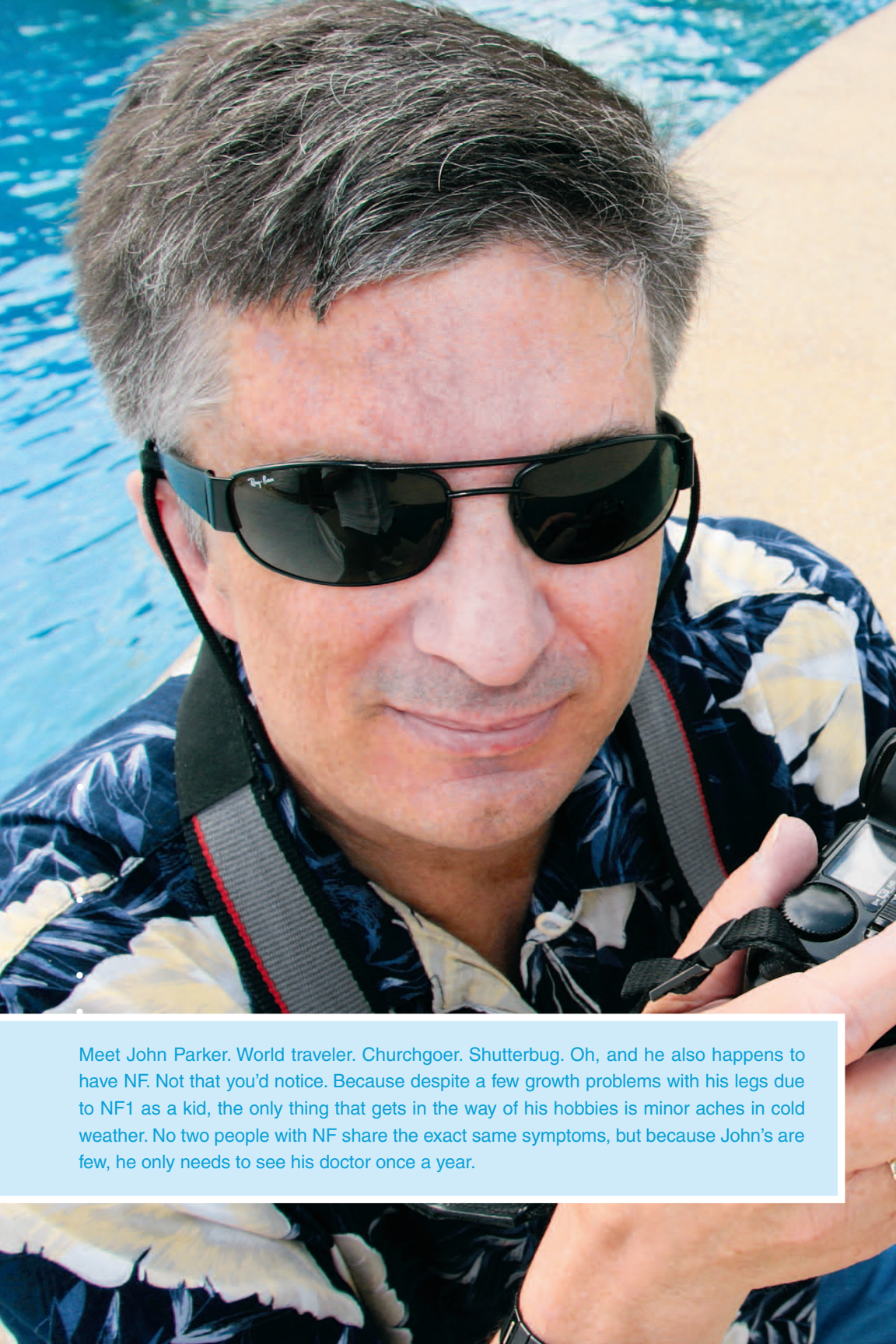
Signs of NF1 are usually visible the first year of life, particularly those on the skin, and almost always by the time a child is about 10 years old. As mentioned before, Lisch nodules on the iris of the eye are commonly developed in teenagers and adults but not usually found in young children. Neurofibromas become evident at around 10 to 15 years of age. Neurofibroma development and growth tend to be associated with hormonal changes that occur in teenage years and during pregnancy. In most cases, symptoms are mild and patients live normal and productive lives; however, NF1 can be severely debilitating.

HOW IS NF1 DIAGNOSED?

The National Institutes of Health offers the following guidelines. Some people with NF1 don't have any changes in their appearance whatsoever. However, when diagnosing, a physician will look for two or more of the following:

- Six or more light-brown skin spots (café au lait macules) measuring more than five millimeters in diameter in patients under the age of puberty or more than 15 millimeters across in adults and children over the age of puberty
- Two or more neurofibromas (tumors that grow on a nerve or nerve tissue under the skin) or one plexiform neurofibroma (involving many nerves)
- Freckling in the armpit or groin area
- Benign growths on the iris of the eye (known as Lisch nodules or iris hamartomas)
- A tumor on the optic nerve (optic glioma)
- Severe scoliosis (curvature of the spine)
- Enlargement or deformation of certain bones other than the spine
- A parent, sibling, or child with NF1

At a young age, Lisa (seated at piano) developed, and still has, some learning and physical difficulties due to tumors growing on her spine. Though doctors were convinced she wouldn't be able to walk, she continues to baffle them, moving around easily with the aid of a walker. With the support of her church, she's also living her dream of becoming a missionary.



Meet John Parker. World traveler. Churchgoer. Shutterbug. Oh, and he also happens to have NF. Not that you'd notice. Because despite a few growth problems with his legs due to NF1 as a kid, the only thing that gets in the way of his hobbies is minor aches in cold weather. No two people with NF share the exact same symptoms, but because John's are few, he only needs to see his doctor once a year.

HOW IS NF1 TREATED?

There is no cure for NF1, so current treatments are aimed at controlling symptoms. Surgery can help some bone malformations. For scoliosis, bone surgery may be combined with the use of a back brace. Painful or disfiguring tumors may be removed with surgery; however, there is a chance that the tumors could grow back. Tumors may become malignant in rare instances (3 to 5 percent of all cases) and could be treated with surgery, radiation, or chemotherapy. Seizures can be treated with antiepileptic drugs, and high blood pressure can be treated with antihypertensives. Learning disabilities respond to appropriate counseling and therapy.

As a baby, Emily Parker suffered a broken tibia, a complication of NF1 that won't heal. But she remains positive about her disorder and helps spread the word about NF, with hope that there will one day be a cure. In fact, Emily was the guest of honor at an NF fund-raiser in her hometown of Sugar Land, Texas. She even introduced the city's mayor at the party.


BASIC TRAIN

ABOUT NF2

NF2 is less common than NF1. NF2 was formerly called central neurofibromatosis. Patients with NF2 may have only a few café au lait spots, light patches of skin, and skin tumors. There will be tumors that affect hearing and balance called vestibular schwannoma, or acoustic neuroma. Vestibular schwannoma tumors get their name from their location and the types of cells in them that cause pressure damage to neighboring nerves. These tumors are located on the vestibular nerve, another branch of the eighth cranial nerve near the auditory nerve. Meningiomas and schwannomas, which occur in individuals with NF2, are tumors that push on the brain and spinal cord. Tumors are benign but can cause serious problems like weakness or seizures. While the problems can be frightening in people who face NF2, there are important advances in research that will give hope to both those with NF1 and NF2.

Because NF can be passed down from parent to child, it's common for more than one family member to have the disease. In the case of the Adairs, father Willie is the only parent with NF. His body is covered from head to toe with noncancerous tumors. Each of the Adair kids has also inherited variations of NF1 from their dad. Willie Jr. has a curvature in his spine called scoliosis. Daughter Amber (right) has had tumors in her brain, stomach, and spine, all requiring surgery. And daughter Elisha hasn't had any serious complications from NF, only a small tumor on her pinky finger. As tough as it can get for them to deal with NF, the Adairs feel lucky to have each other as a kind of "built-in" support group.

The Fuhrmans are another NF family whose members have different symptoms. Dad Michael has small tumors on his neck and stomach, while sons Matthew and Sammy each have learning disabilities. As a result, both boys attend private schools where they receive the special attention they need to do well in school.

WHEN DO SYMPTOMS APPEAR WITH NF2?

For some people, the signs of NF2 are detectable in childhood, but for the majority, NF2 is not discovered until puberty or later. Hearing loss may be noticed in the teens. Changing in hearing may occur in one or both ears, or there may be other early symptoms that may include tinnitus (ringing noise in the ear) and poor balance. Pressure from the tumors may cause headaches, facial pain, or facial numbness.

HOW IS NF2 DIAGNOSED?

In diagnosing NF2, a physician looks for two or more of the following:

1. Bilateral eighth nerve tumors
2. A parent, sibling, or child with NF2 and a unilateral eighth nerve tumor
3. A parent, sibling, or child with NF2 and any two of the following:
   - glioma
   - meningioma
   - neurofibroma
   - schwannoma
   - cataracts at an early age

Denise Terrill has lived with mild and severe NF2 complications almost all of her life. An athlete for many years, at the age of 20 she was left completely paralyzed after several operations to remove tumors from her spinal cord. “When I look at her, my problems aren’t so big,” her dad says. “Her mission is to give inspiration to people to realize their problems are not insurmountable.” Denise’s condition has also inspired her family to organize The Denise Terrill Charity Golf and Tennis Classics, annual fund-raisers that help support critical NF research.

Brazos was diagnosed with NF2 at 10 years of age. Now 21, he has already undergone many successful surgeries to remove several brain tumors but still faces the possibility of both vision and memory loss, as well as paralysis. Though there are times when he feels angry or depressed, Brazos accepts the disease as his reality and tries to maintain a positive attitude. He continues his education at Richland College in Dallas, Texas, chasing his Marketing and Advertising degree, and spends most of his free time offshore fishing. “Life is not over,” he explains. “You have to overcome obstacles, learn from them, and not take life for granted.”

HOW IS NF2 TREATED?

Treatments for NF2 are also aimed at controlling symptoms. With improved technology, MRIs (magnetic resonance imaging) can detect tumors as small as a few millimeters in diameter, allowing for early treatment. Surgery is an option to remove tumors but may result in hearing loss. Some other options may include partial removal of tumors and radiation. Seizures can be treated with antiepileptic drugs.

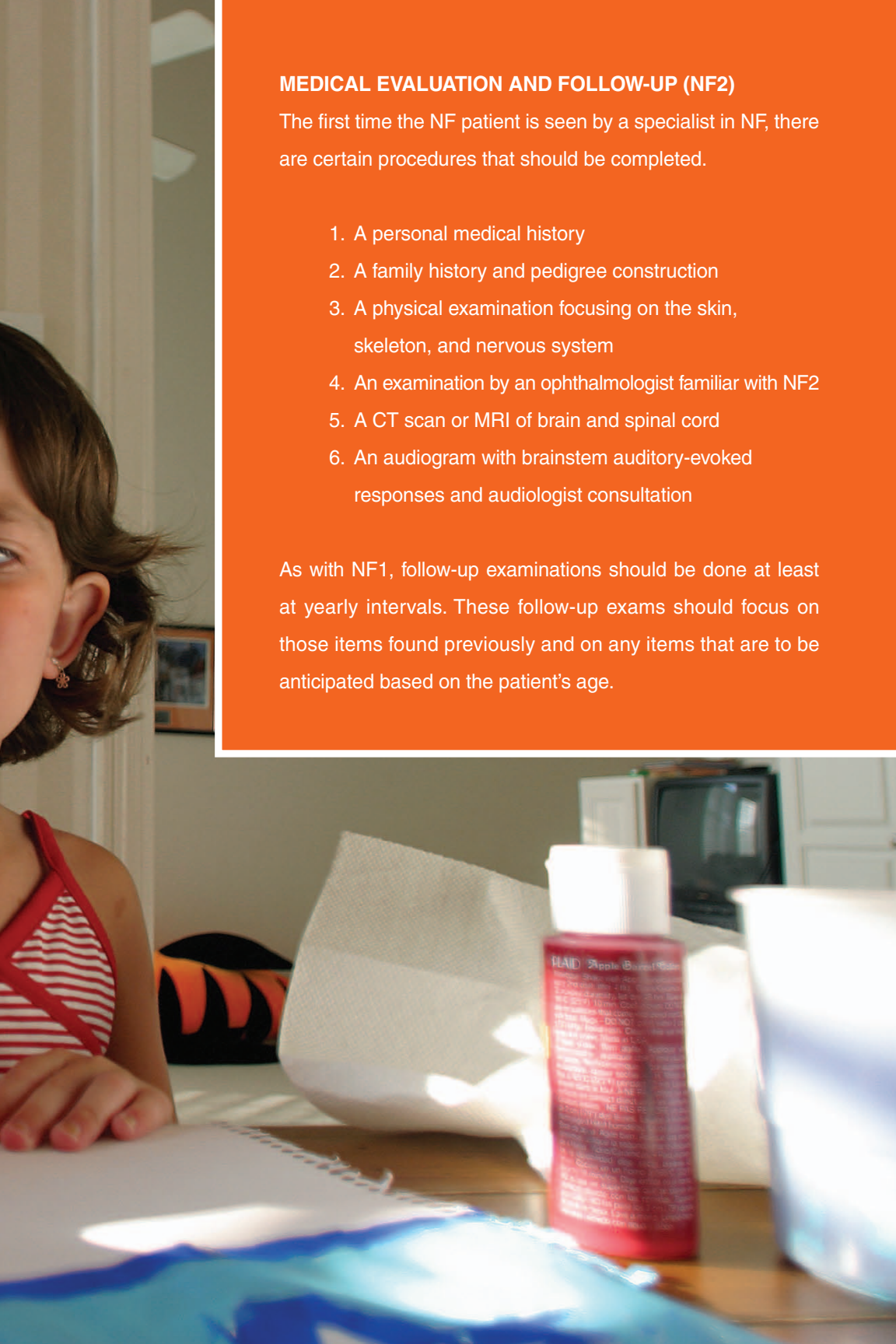
MEDICAL EVALUATION AND FOLLOW-UP (NF1)

The first time the NF1 patient is seen by a specialist in NF, there are certain procedures that should be completed.

1. A personal medical history
2. A family history and pedigree construction
3. A physical examination focusing on the skin, skeleton, and nervous system
4. A slit lamp examination by an ophthalmologist familiar with NF
5. IQ, psychological, or cognitive testing is warranted for children in school or adults with reading, work, or learning problems
6. A CT scan or MRI of brain and orbits
7. Regular x-rays of any bony abnormality
8. An audiogram for NF1 patients with hearing or learning problems

Follow-up examinations should be done at least at yearly intervals. These follow-up exams should focus on those items found previously and on any items that are to be anticipated based on the patient's age.

Born with two large birthmarks, it wasn't clear right away that Meredith had NF. But when a lump over her right eyebrow was discovered, her pediatrician recognized it as a sign of NF1. For new patients, Meredith's mom offers this advice – "Don't freak out! Be as proactive as possible and know that your doctor will treat each NF patient reactively."



MEDICAL EVALUATION AND FOLLOW-UP (NF2)

The first time the NF patient is seen by a specialist in NF, there are certain procedures that should be completed.

1. A personal medical history
2. A family history and pedigree construction
3. A physical examination focusing on the skin, skeleton, and nervous system
4. An examination by an ophthalmologist familiar with NF2
5. A CT scan or MRI of brain and spinal cord
6. An audiogram with brainstem auditory-evoked responses and audiologist consultation

As with NF1, follow-up examinations should be done at least at yearly intervals. These follow-up exams should focus on those items found previously and on any items that are to be anticipated based on the patient's age.

An optic nerve glioma, or growth on the nerve of the eye, is another symptom of NF1. Jacob found out he had one after his first yearly MRI, and luckily, his condition hasn't changed. It doesn't affect his vision, and it hasn't stopped him from playing video games, the trombone, and what seems like about 1,000 other activities, either.

Some people become discouraged when they find out they have NF. Then there's Kyleigh. Even though she has endured many of the unpleasant effects of NF1 – headaches, tumors, and scoliosis – she still enjoys cheerleading, piano lessons, singing, playing, and just about everything else a normal diva her age would.

LEARNING DISABILITIES AND NF

Many children with neurofibromatosis have learning difficulties in school even though they are intelligent and capable. Some have difficulty focusing on the schoolwork itself; others have a hard time making or keeping friends. All these factors can make going to school unpleasant. It's the school's responsibility to provide an environment to promote success for all students. By law, schools cannot discriminate against children with disabilities, such as neurofibromatosis.

If an educational need exists, children with neurofibromatosis should be considered for special education services under the category of Other Health Impaired (OHI). A physician may complete the OHI form to begin the process of scheduling an Admissions, Review and Dismissal (ARD) Committee meeting in which an Individual Educational Plan (IEP) is formulated. The IEP governs the child's day at school. Appropriate placement and accommodation strategies can be individualized according to each student's needs.

Parents should ask teachers whether their child is having difficulty in school and determine if a special learning evaluation is needed. With help, NF children can be successful in school.

WHAT NOW?

Learn all you can about NF.

Again, there isn't a cure – yet. NF is a lifelong condition, and the best way to stay on top of it is to educate yourself. Find a doctor who treats NF patients and is familiar with the disorder. Ask questions. Locate a support group through the Texas Neurofibromatosis Foundation so you can talk to others who are affected by the disease. Their stories and experiences may give you the kind of insight even a physician may not be able to provide. Just knowing more about NF will help give you the strength to deal with the challenges you may face.

It's important that you take note of any changes that might be due to NF. Keep good records of these problems. This will help you discuss changes and possible solutions with your doctor.

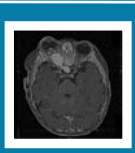
You've probably heard it before. But if you take one thing away from reading this, remember – you are not alone. Thousands of people of all ages are affected by NF. Because there isn't anything you can do to prevent symptoms from happening, there may be times when you feel upset or helpless. You may also think there's no way anyone can understand what it's like for you to have NF. Each person handles it in his or her own way, yet there are things they share in their daily routines. Some choose to remain in the background. Others, like those featured in this booklet, are spokespersons in their communities as well as liaisons for other patients.

To date, little Drake is only mildly affected by NF1. He's tackled digestive issues, along with gross and fine motor delays, with the help of several doctors and physical therapists – usually in one of his many action figure costumes.

NF1 Symptoms

seizures
headaches
brain tumors
brain blood vessel defects
learning disabilities
mental retardation
macrophely – oversized head

optic glioma
(tumor of the nerve)



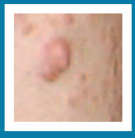
Lisch nodules
(benign pigmented tumors in the iris)

speech impairments

high blood pressure

freckling
(where skin meets skin: armpits, groin, under the breasts)

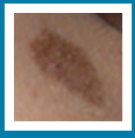
neurofibroma
(may appear anywhere on skin)



scoliosis
(abnormal curvature of the spine)

digestive tract neurofibromas
(may cause pain, vomiting, chronic constipation or diarrhea)

café au lait spots
(similar to dark birthmarks – may occur anywhere)



early or delayed puberty
(neurofibromas may increase in size and number and may also occur during pregnancy)

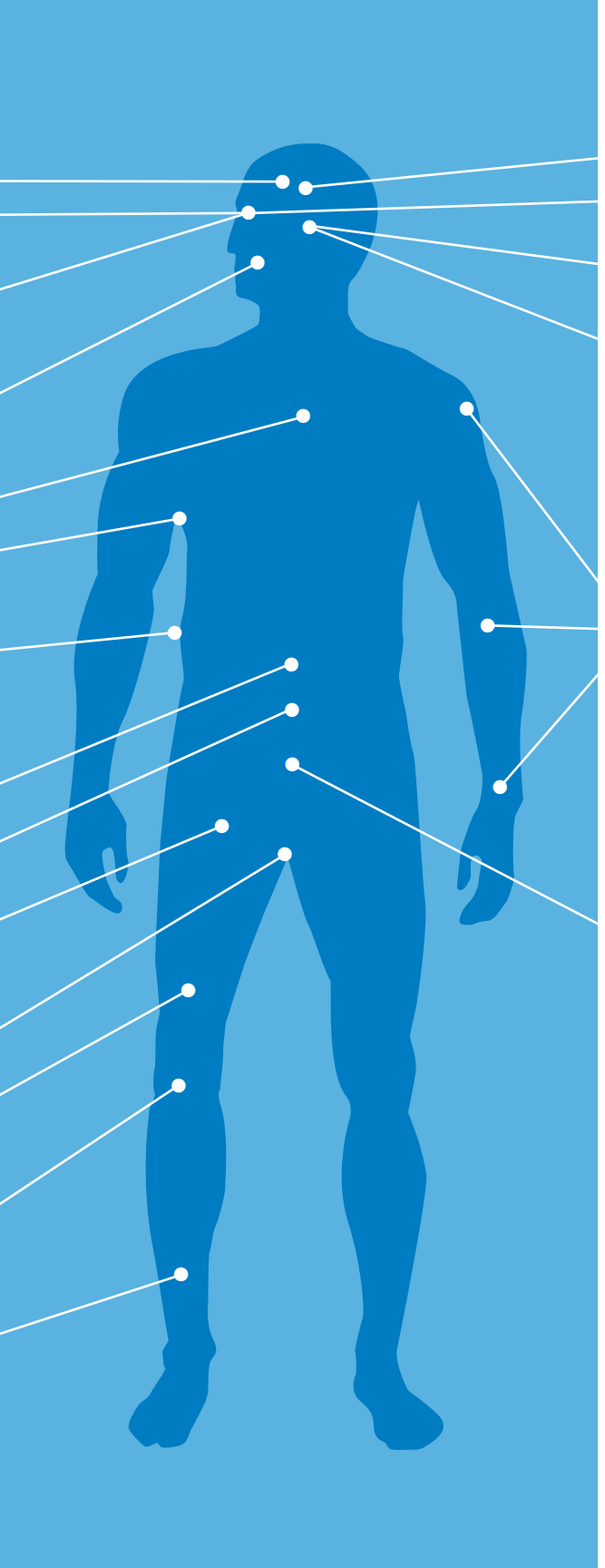
pseudarthrosis
(failure of a fracture to heal)

knock-knees or bowlegs
(genuvalgum or genuvarum)

bone deformities

Other complications may include delay in learning to talk or walk, short stature, poor school performance, increase in size and number of tumors during pregnancy, severe itching, psychosocial burdens, and cancer.

Source: NF, Inc.



NF2 Symptoms

meningioma (and other brain tumors)

cataracts (visual impairment/blindness)

tinnitus (ringing in the ears)

hearing loss (and/or deafness)

bilateral vestibular schwannomas (acoustic neuromas)

schwannomas of the peripheral nerves and skin tumors

spinal tumors

Balance problems, dizziness, seizures, headaches, and general muscle wasting can be associated with NF2.

NF is only one part of your life, so try not to let it define your life. It's this kind of attitude that inspires research that will one day control and, ultimately, close the book on NF for good. Meanwhile, we'll keep sharing our stories. When you're ready, we hope you'll share yours, too. And we hope that the stories in this book have helped define the condition for you in terms you can relate to. The challenges you'll face with NF may be difficult. But you'll always have the continued support of the NF community here in Texas … and beyond.

The Texas NF Foundation is also dedicated to creating as much awareness about the disease as possible. Along with NF education, lobbying for research funding in Washington, D.C., is a big priority. Together with The Denise Terrill Charity Classics, Texas NF has helped fund key research projects and clinical applications to find a cure for NF.

These grants have included the brightest scientists from top institutions such as:

- Baylor College of Medicine
- Children's Medical Center of Dallas/NF Clinic
- Cold Spring Harbor Laboratory
- Harvard Medical School
- Ludwig Institute of Cancer
- University of California
- University of Guam
- University of Texas M.D. Anderson Cancer Center
- UT Southwestern Medical Center
- Yale University

WHERE CAN I GET HELP?

The Texas Neurofibromatosis Foundation
800-WHAT IS NF (800-942-8476)
www.texasnf.org

The Texas Neurofibromatosis Foundation is committed to meeting the needs of people challenged with neurofibromatosis by providing care, comfort, support, information, education, funding, and other resources for its treatment, prevention, and eventual cure.

The foundation organizes support gatherings across the state of Texas, social outings, the annual NF Family Camp, and the annual NF Symposium. The foundation can help make referrals to NF Clinics or other doctors if you need help locating a doctor. Educating patients, families, physicians, teachers, and the general public about neurofibromatosis is part of the foundation's public education program.

HOW CAN I HELP?

There are numerous ways to help our cause. Volunteer at the office or during one of our special fund-raising events. You can also make a donation to help carry out our mission and programs. Contributions can be made by calling our office at 972-868-7943 or visiting www.texasnf.org.

NF CLINICS IN TEXAS

Baylor College of Medicine/
Texas Children's Hospital of Houston
832-822-4280
Clinic Chief: Sharon Plon, M.D., Ph.D.

Children's Medical Center of Dallas
214-456-6139
Medical Director: Arlynn F. Mulne, M.D.

Cook Children's Genetics, Fort Worth
682-885-2182 or 800-266-5514
Medical Director: Mary K. Kukolich, M.D.

University of Texas M.D. Anderson
Cancer Center, Houston
800-392-1611 or 713-792-6161
Medical Director: John M. Slopis, M.D.

Methodist Children's Hospital of
South Texas in San Antonio
210-575-7371 or 800-297-1021
Clinic Director: Patricia R. Garcia, R.N.

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Tonsgard, James H. *Understanding Neurofibromatosis: An Introduction for Patients and Parents*. Published by Illinois Neurofibromatosis, Inc. (1994).

"Neurofibromatosis Fact Sheet." Prepared by Office of Communications and Public Liaison, National Institutes of Health (NIH), National Institute of Neurological Disorders and Stroke. Bethesda, MD.

ADDITIONAL RESOURCES

Children's Tumor Foundation www.ctf.org Tel: 800-323-7938

National Cancer Institute (NCI) www.cancer.gov
Tel: 800-4-CANCER (422-6237) 800-332-8615 (TTY)

National Institutes of Health (NIH) www.nih.gov

National Institute of Neurological Disorders and Stroke (NINDS)
www.ninds.nih.gov

Neurofibromatosis, Inc. (NF Inc.) www.nfinc.org Tel: 800-942-6825 or 301-918-4600

Acoustic Neuroma Association www.anausa.org
Tel: 770-205-8211 Fax: 770-205-0239

House Ear Clinic www.houseearclinic.com

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GLOSSARY OF TERMS

Atrophy – Decrease in size or wasting away of a body part or tissue.

Auditory Nerve – Any of the eighth pair of cranial nerves connecting the inner ear with the brain and transmitting impulses concerned with hearing and balance.

Benign – Not malignant or not cancerous.

Café au lait – Brown oval spots on the skin the color of coffee with milk.

Cataract – Clouding of the lens of the eye or of its surrounding transparent membrane that obstructs the passage of light.

Chemotherapy – The use of chemical agents in the treatment or control of disease.

Chromosomes – The basic units of heredity. The nucleus of each body cell contains 23 pairs of chromosomes.

Dominant – Being the one of a pair of bodily structures that is the more effective or predominant in action.

Gene – The basic unit of heredity. Thousands of genes, arranged in specific linear order, form a chromosome. Genes come in pairs; each pair is located on one chromosome, with the matching gene on the other chromosome of that pair.

Genetic – Inherited or basic, relating to information contained on genes.

Glioma – A type of brain tumor.

Learning Disability – A disorder that affects people's ability to either interpret what they see and hear or to link information from different parts of the brain. These limitations can show up in many ways: as specific difficulties with spoken and written language, coordination, self-control, or attention.

Lisch Nodule – Spot on the iris, the colored part of the eye.

Meningioma – A benign tumor of the covering of the brain.

MRI (Magnetic Resonance Imaging) – A diagnostic technique that uses magnetic energy to image the brain and body.

Mutation – A permanent change in the genetic material, usually in a single gene.

Neurofibroma – A benign tumor caused by proliferation of Schwann cells and fibroblasts.

Neurofibromatosis – A genetic disorder that primarily affects the development and growth of neural (nerve) cell tissues.

Neurofibrosarcoma – Also known as peripheral nerve sheath tumor; a malignant tumor that develops in the cells surrounding these peripheral nerves.

Optic Glioma – Tumor affecting the optic nerve.

Plexiform Neurofibroma – A diffuse, flat type of growth. Usually occurs below the skin internally.

Pseudarthrosis – Failure of a fracture to heal.

Radiation Therapy – The use of high-energy rays or particles to treat disease.

Sarcoma – Malignant soft tissue tumor.

Schwann Cell – The cell in which myelin is composed.

Schwannoma – A benign tumor caused by proliferation of Schwann cells.

Scoliosis – Curvature of the spine.

Spontaneous Mutation – A change in a gene occurring with no identifiable cause.

Tinnitus – Ringing noise in the ear.

Tumor – An abnormal mass of tissue that results from excessive cell division.

Vestibular Schwannoma (Acoustic Neuroma) – Benign tumor of the eighth cranial nerve.


"Elisabeth, you make the world a better place, with the kindness of your smile and your love, and your beauty will live on and on …" are the words sung by country music star Billy Gilman. They are the words that have immortalized my sister forever. They are the words that spoke of a girl named Elisabeth who lived a life of love, poise, courage, confidence, and a deep belief in God. These words made her a role model and a heroine for so many people who would never even know her.

Elisabeth introduced NF to my family when she was very young – before I was even born. Growing up, my brother and I knew that Elisabeth had to go to the doctor a little more often than we did, but we never thought she was different from us. We always got to go to these fun camps and great parties my parents would organize for other NF families. My whole family became so involved with NF, which meant fun events and parties for us all of the time.

For over 18 years we watched Elisabeth do just about everything anyone else could do. She was a good student, a good dancer, a good Christian, and especially a good friend. She was on a competitive dance team. She went to college. She joined a sorority. She had it all.

The last few years of Elisabeth's life were hard for her, and hard for us. But through it all, we learned the true value of family. We faced challenges that few people know, but we also experienced a deeper love that most families will never experience. We would never have had this without Elisabeth.

In 2003, Elisabeth's hard-fought battle with NF came to an end. We miss her so much, but my family and I, as well as our friends and acquaintances and anyone else who knew Elisabeth, learned about life's challenges and learned how one person can make such a difference. We dedicate this book to the families you will read about who also know of this love, this courage, and this disease called NF. We know that one day we won't have a book like this because NF will not be here anymore. For that day, we know Elisabeth's life moved us one step closer to a cure, and that she really did "make the world a better place."

Catherine Wagner
Elisabeth's sister

In Honor of Meredith Lyon

The Texas NF Foundation was an incredible source of information, support, and love as our daughter, Meredith Lyon, fought NF. Meredith was one of the rare cases when NF converts to neurofibrosarcoma, a form of cancer.

If you happen to be one of the few who face the conversion to neurofibrosarcoma, we would like to share our learning with you. We worked with the best doctors and hospitals in the country. We learned how to fight this disease. We would like to reach out to you and share what we learned.

There are no manuals. There is very little information on how to fight. There are only the experiences and lessons from those who have gone before us.

Meredith would want us to help you. The happiness and well-being of others is all Meredith really cared about. Please contact us. We did it all, tried it all, and want you to learn from her experience.

The Lyon Family
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