

# NEWLY DIAGNOSED WITH SCHWANNOMATOSIS: A GUIDE TO THE BASICS



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1-800-323-7938

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH



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## NEWLY DIAGNOSED? You Are Not Alone

We at the Children's Tumor Foundation (CTF) understand that many questions and concerns arise after receiving a diagnosis of schwannomatosis, a form of neurofibromatosis, or NF. There's a lot of information to absorb at one time, and you probably want to know how your diagnosis will impact your life. It can be helpful to remember that different people may deal with health-related news in different ways. While some prefer to digest small bits of information at a time, others like to get as much information as possible right away. Both of these approaches are perfectly normal.

It's important to know that the symptoms of schwannomatosis vary widely, and most people with the condition continue to lead full and active lives under the care of an experienced specialist who can manage their symptoms and watch for potential complications. This brochure is designed to give you essential information about schwannomatosis as well as provide key advice and resources so that you can take care of your health and continue to get the most out of life.

As you begin your journey of learning more about schwannomatosis, we also want you to know that you are not alone. The Children's Tumor Foundation has many resources available for adults and children living with NF throughout the United States. We ask you to think of us as your extended family. These resources include clinics throughout the country, and various events that you can attend to help you meet more members of the NF community around you.

Dealing with a diagnosis of schwannomatosis can be hard. We know that the current lack of a cure and the unpredictability of the disorder do not make things any easier. However, there are things that you can do to help make this journey feel a little more manageable:

- **Get the facts** – Read the “NF Basics” page in this booklet, or visit the Foundation’s website at **ctf.org** to learn more about the three types of NF.
- **Find a doctor that knows about NF** – We understand how difficult it is to find healthcare professionals who have experience with schwannomatosis. We are constantly working to expand our clinic network to add to the list of professionals available on our website.
- **Connect** – The NF Forum is a national patient and family gathering that allows those living with NF and their families to connect, support, and learn from one another while attending seminars on relevant topics pertaining to NF. Find out more at **ctf.org**.
- **Sign up for research** – Join the NF Registry to learn about, and participate in, advanced scientific research on all forms of NF at **nfregistry.org**.
- **Get in touch** – Reach out to your regional contact on CTF’s staff, listed on the Foundation’s website at **ctf.org**.
- **Get involved** – National programs like NF Walk, NF Endurance, NF Camp, and Racing4Research are great ways to empower yourself and your community in the fight for treatments and a cure for NF. Getting involved is a great way to meet others who are also affected by NF.
- **Stay in touch** – Visit the CTF website, “like” our Facebook page, and follow us on Twitter and Instagram for all the latest news and information.
  - Web: [ctf.org](http://ctf.org)
  - Facebook: [facebook.com/childrenstumor](https://facebook.com/childrenstumor)
  - Twitter: [twitter.com/childrenstumor](https://twitter.com/childrenstumor)
  - Instagram: [instagram.com/childrenstumor](https://instagram.com/childrenstumor)
  - YouTube: [youtube.com/childrenstumor](https://youtube.com/childrenstumor)



“There are so many unknowns with NF, as in life, and it’s easy to let your mind wander. However, I have learned that living each day to its fullest and finding the joy in everyday life is the best way to make it through those very trying times. There are so many more things in life that I have been blessed with and that is what I choose to focus on. I won’t let NF define who I am. Most of all, it helps to know that I am not alone.”

- Michele Baumbaur, who lives with schwannomatosis

## The Children’s Tumor Foundation

Founded in 1978, the Children’s Tumor Foundation (CTF) began as the first grassroots organization solely dedicated to the goal of finding treatments for NF. Today, CTF is a highly recognized national nonprofit foundation, the leading force in the fight to end NF, and a model for other innovative research endeavors.

**The Mission of the Children’s Tumor Foundation:**

Drive research, expand knowledge, and advance care for the NF community.

**Our Vision:** End NF

Please feel free to call the Children’s Tumor Foundation for information at 1-800-323-7938, or email [info@ctf.org](mailto:info@ctf.org).

## NF Basics

**Neurofibromatosis (NF)** includes at least three distinct disorders caused by an abnormality in any one of several genes. These disorders include neurofibromatosis type 1 (NF1), neurofibromatosis type 2 (NF2), and schwannomatosis. NF occurs in all populations equally, regardless of gender or ethnicity. One type cannot turn into another type. While NF1 is caused by a change, or mutation, in a gene located on chromosome 17, both NF2 and schwannomatosis are caused by mutations in genes located on chromosome 22 (although other genes not yet identified may also be associated with schwannomatosis).

**Neurofibromatosis type 1 (NF1)**, formerly known as von Recklinghausen NF or peripheral NF, is the most common of the three types of neurofibromatosis and is also one of the most common genetic neurological disorders, affecting about 1 in 3,000 people throughout the world. The disorder is characterized by multiple café au lait (light brown) skin spots and neurofibromas (small benign growths) on or under the skin. Some people with NF1 develop large, potentially disfiguring neurofibromas. About 50% of people with NF1 also have learning challenges. Softening and curving of bones and curvature of the spine (scoliosis) occur in some people with NF1. Occasionally, tumors may develop in the brain, or arise from cranial or spinal nerves. While NF tumors are generally not cancerous, they may cause health problems by pressing on nearby body tissues. Sometimes a benign tumor may become malignant (cancerous), but 85 to 90% of people with NF1 will never develop a malignant tumor related to neurofibromatosis.

**Neurofibromatosis type 2 (NF2)** is less common than NF1, affecting about 1 in 25,000 people. The disorder is characterized by the development of benign tumors called vestibular schwannomas (also called acoustic neuromas) on the nerve that carries sound and balance information from the inner ear to the brain (the eighth cranial nerve). These tumors often affect both ears, and may lead to partial or complete hearing loss. NF2 can also cause schwannomas to develop on other cranial or peripheral nerves. People with NF2 can also develop other tumors such as meningiomas (tumors of the membranes surrounding the brain and spinal cord) and ependymomas (tumors that develop from cells lining the ventricles of the brain and center of the spinal cord). The disorder can also cause the development of cataracts, potentially compromising vision. Most people develop symptoms in the late teen and early adult years, although about 10% of people develop symptoms during late childhood. The most common symptoms of NF2 include ringing in the ears (tinnitus), gradual hearing loss, and balance problems.

**Schwannomatosis** is a rare form of neurofibromatosis that has only recently been identified. The genetic disorder affects about 1 in 40,000 people and causes the development of benign tumors—called schwannomas—usually on spinal and peripheral nerves. These tumors develop when Schwann cells, which form the insulating cover around nerve fibers, grow abnormally. Tumor development appears to be primarily related to a change, or mutation, in certain genes that help regulate cell growth in the nervous system. These mutations prevent the genes from making normal proteins that control cell proliferation, allowing cells to multiply excessively and form tumors. These tumors may cause pain that can be hard to manage. Schwannomatosis is usually diagnosed in adulthood.

## Understanding Schwannomatosis Symptoms

Symptoms of schwannomatosis are usually detected between the ages of 30 and 60, though they can occur at any age. The most common symptom is chronic pain, which can occur anywhere in the body, believed to be caused at least in part by schwannomas (benign tumors) pressing on nerves. In some cases, the pain that people experience is disproportionate to the size of the tumors that are present. Also, the intensity and frequency of pain varies significantly among individuals who are affected. While most people with schwannomatosis experience some degree of pain that requires medical management, a small number of people have only mild pain. Others may experience severe pain that interferes with daily living. Although some people may also experience neurological symptoms, many people with schwannomatosis experience pain as the only symptom for several years before the source of the pain is identified. For this reason, the condition is often difficult to diagnose.

In addition to the symptom of pain, some people with schwannomatosis experience neurological and other symptoms, which may include:

- Numbness or tingling
- Weakness, including facial weakness
- Bowel dysfunction or difficulty urinating
- Vision changes
- Headaches

### Clinical Features

The main clinical feature of schwannomatosis is the development of schwannomas, distinctive tumors that grow on peripheral nerves (nerves of the central nervous system). These tumors develop from Schwann cells, nerve sheath cells that support and protect nerve cells and serve as insulation needed to conduct nerve impulses. Schwannomas are very homogeneous tumors, which means they consist only of Schwann cells. These often slow-growing tumors remain on the outside of the nerve, but they can push the nerve aside or press it against a bony structure or other tissue, causing pain and complications.

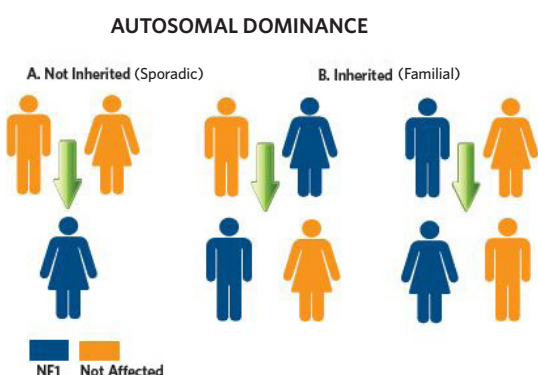
Unlike neurofibromas found in people with NF1, schwannomas are typically located deeper inside the body, although sometimes a physician may be able to palpate them during a physical exam. Some people with schwannomatosis develop tumors throughout their body, while others may have only one or two tumors throughout their lifetime. About one-third of individuals with schwannomatosis have a distinctive form of the disorder, called *mosaic* or *segmental* schwannomatosis, that causes tumor growth only on one side or one part of the body, such as an arm, a leg, or a segment of the spine.

Schwannomas are the same type of tumors that develop in people with NF2, although schwannomatosis lacks many of the clinical features common in people with NF2. The most important distinction is that people with schwannomatosis typically don't develop tumors on the vestibular nerve (vestibular schwannomas) that cause hearing loss in individuals with NF2, although emerging clinical data indicate that vestibular schwannomas may occur in some people with schwannomatosis. Also, other types of tumors that can occur in people with NF2 (including meningiomas, ependymomas, and astrocytomas) don't occur in those with schwannomatosis, with rare exceptions. Features of NF1, such as learning problems and café-au-lait spots, are also not present in people with schwannomatosis.

## Inheritance and Genetics of Schwannomatosis

### Familial Cases

Although schwannomatosis is a genetic disorder, the inheritance patterns are complex and less clear than for both NF1 and NF2. Some cases of schwannomatosis are familial, or inherited, with more than one person in a family being affected with the disorder. Inherited forms of schwannomatosis account for only about 15% of all cases. In familial cases, schwannomatosis is inherited based on an autosomal dominant pattern. Autosomal



dominant means that inheriting an abnormal gene from only one parent can cause the disorder, even though the matching gene from the other parent is normal. A parent with an autosomal dominant disorder has a 50% chance of passing along the disorder to a child.

However, in familial cases of schwannomatosis, symptoms of the disorder may skip generations due to a

genetic phenomenon called *incomplete penetrance*. Penetrance refers to the proportion of people with a particular genetic change—such as a mutation in a specific gene—who show signs and symptoms of a genetic disorder. If a genetic condition has complete penetrance, symptoms are always visible. However, if a disorder has incomplete penetrance, as with schwannomatosis, not everyone who inherits the mutation will show symptoms. Unlike NF1 and NF2, people may carry a schwannomatosis gene mutation but never develop symptoms due to incomplete penetrance.

### Sporadic and Mosaic Cases

Most people with schwannomatosis are the first in their family to be diagnosed with the disorder and are referred to as sporadic cases. But people who are the first in their family can then pass it on to their offspring, who will have familial cases. Some people have schwannomatosis features only on one side or one part of the body, a condition which is referred to as mosaic or segmental schwannomatosis. This form of the disorder may involve mutations in currently identified genes known to be associated with schwannomatosis. NF2 and schwannomatosis share some clinical features and, particularly in mosaic cases, it can be difficult to distinguish between the two forms.

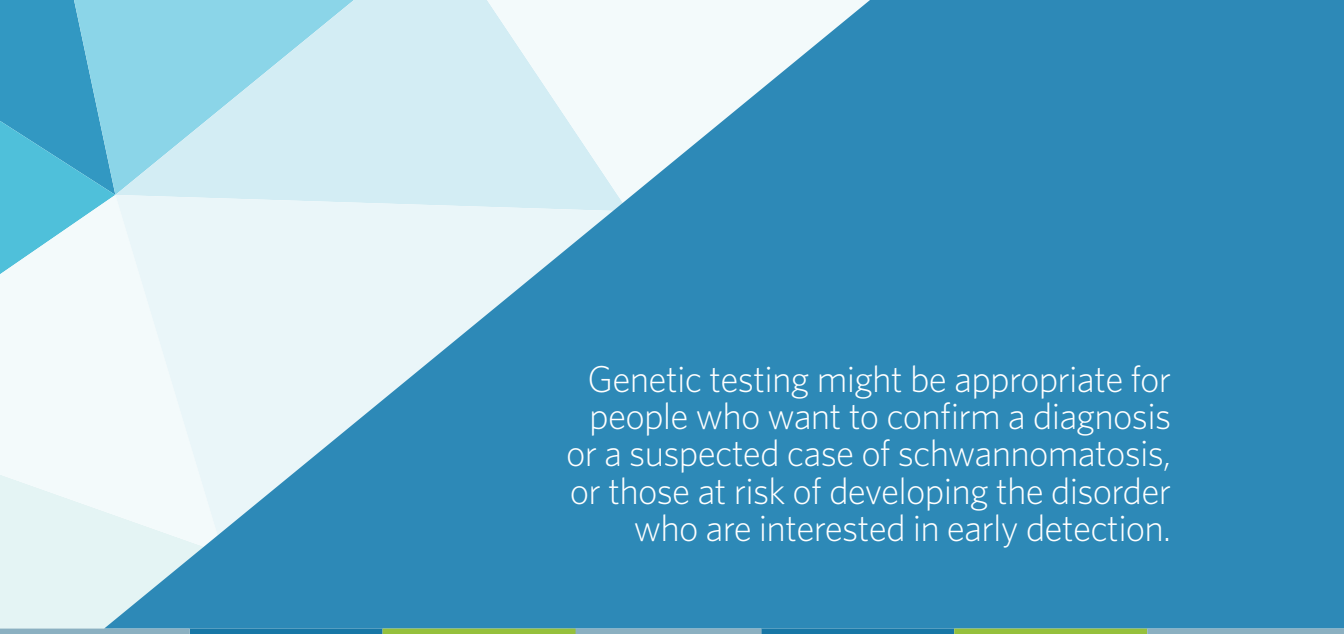


“We took a lot of helpful and educational information away with us after attending the Children’s Tumor Foundation NF Forum, and it was a huge comfort to feel as though we are not alone in the challenges this disorder brings. The other attendees became our allies and friends.”

- Jeanette Held lives in Bristol, WI, and is the mother of 22-year-old twin sons, Travis and Trent, both of whom have schwannomatosis.

### Genetic Mutations Associated with Schwannomatosis

A mutation, or change, in a tumor suppressor gene located on chromosome 22 that was first identified in 2007—called *SMARCB1*, or *INI1*—is associated with about 30 to 50% of familial cases and 7 to 10% of sporadic cases of schwannomatosis. This discovery has led to the development of genetic testing that can detect mutations in this gene, using blood or tumor samples, to confirm a diagnosis of schwannomatosis. For many people with schwannomatosis, however, a mutation in the *SMARCB1* gene is not the cause of the disorder. Research has led to the recent discovery of a novel gene also located on chromosome 22—called *LZTR1*—that is associated with about 30 to 40% of familial and 20 to 30% of sporadic schwannomatosis cases in people who don’t have a mutation in the *SMARCB1* gene. The identification of the new *LZTR1* gene and its mutations has led to increasingly refined genetic testing that can help to confirm a diagnosis of schwannomatosis in some people who don’t have a mutation in the *SMARCB1* gene.



Genetic testing might be appropriate for people who want to confirm a diagnosis or a suspected case of schwannomatosis, or those at risk of developing the disorder who are interested in early detection.

### Genetic Testing

Genetic mutations associated with schwannomatosis can be detected with genetic testing using DNA extracted from blood or tumor samples. Analysis of DNA extracted from at least two tumor samples from different anatomical locations, when possible, is the most sensitive and specific method of determining the presence of chromosome 22-related schwannomatosis. An ideal testing protocol for schwannomatosis includes mutation analyses for the *NF2*, *SMARCB1*, and *LZTR1* genes in blood and tumor samples.

Genetic testing for the currently known schwannomatosis genes is available. For people with mosaic schwannomatosis, genetic testing can be more complicated than for people who do not have a mosaic form of this condition. However, it's important to understand that current genetic testing doesn't reveal a mutation in all affected individuals, and there may be additional genes responsible for the disorder in some people yet to be discovered. It is a good idea for anyone with questions about genetic testing and reproductive options in schwannomatosis, including prenatal testing, to meet with a medical geneticist or genetic counselor to learn more about his or her individual case.

### The Role of Genetic Counseling

A genetic counselor can offer help in the following key areas:

- Provide information about the complex inheritance patterns involved in schwannomatosis;
- Explain the testing options available to you and discuss the benefits and limitations of genetic testing;
- Interpret and explain the results of genetic testing for schwannomatosis.

## How Is the Diagnosis Made?

Schwannomatosis can be difficult to diagnose because symptoms vary widely among affected individuals, and many of the symptoms are shared by other disorders. For these reasons, it's important to know that an accurate diagnosis of schwannomatosis is best made by a physician with expertise in the diagnosis and treatment of neurofibromatosis. Specific clinical and molecular diagnostic criteria have been established based on a consensus of experts. The following criteria, while written and intended for clinicians, may be helpful in enhancing your understanding of the diagnostic procedures for schwannomatosis and in your discussions with clinicians about your own individual diagnosis.

### Criteria for a Clinical Diagnosis—Includes Any ONE of the Following:

- Two or more non-intradermal schwannomas, one with a pathological confirmation, including no bilateral vestibular schwannoma by high-quality MRI (a detailed study of internal auditory canal with slices no more than 3mm thick).  
*Note: Some mosaic NF2 patients will be included in this diagnosis at a young age and some schwannomatosis patients have been reported to have unilateral vestibular schwannomas or multiple meningiomas.*
- OR - One pathologically confirmed schwannoma or intracranial meningioma AND an affected first-degree relative (such as a parent or a sibling).
- OR - It will be considered as a possible diagnosis if there are two or more nonintradermal tumors but none has been pathologically proven to be a schwannoma; the occurrence of chronic pain in association with the tumor(s) increases the likelihood of schwannomatosis.

Patients with the following characteristics do not fulfill a diagnosis for schwannomatosis:

- A germline pathogenic NF2 mutation
- Fulfillment of the diagnostic criteria for NF2
- A first-degree relative with NF2
- Radiographic evidence (image scans) of a nonvestibular schwannoma

### Criteria for a Molecular Genetic Diagnosis

- Two or more pathologically proved schwannomas or meningiomas AND genetic studies of at least two tumors with loss of heterozygosity (LOH) for chromosome 22 and two different *NF2* mutations; if there is a common *SMARCB1* mutation, this defines *SMARCB1*-associated schwannomatosis.
- One pathologically proved schwannoma or meningioma AND germline *SMARCB1* pathogenic mutation.

## Medical Management of Schwannomatosis

There is currently no cure for schwannomatosis and no medication has been shown to be effective in treating schwannomas. Management of the condition is based on the specific symptoms a person develops. Because schwannomatosis can cause pain, neurological symptoms, and other potentially serious complications, it's important to seek treatment from a neurologist, neurosurgeon, or geneticist who is experienced with schwannomatosis, preferably in an NF clinic that provides multidisciplinary care.

### Surgical Intervention and Pain Management

Some people with schwannomatosis don't have active symptoms and are only diagnosed based on the presence of multiple schwannomas. Management for these individuals can include an annual neurologic evaluation and imaging as recommended by an experienced specialist. For people who experience pain related to schwannomatosis, treatment and medical management of the condition often involves surgery to remove schwannomas and lessen the associated nerve pain. Complete removal of the tumors often helps pain to subside, although the pain may recur if other tumors form. In some people, surgery may not reduce pain and can sometimes lead to an increase in painful symptoms. Surgery may also be considered for people who have tumors that are causing neurologic or organ-related complications. Anytime surgery is considered for a person with schwannomatosis, it's important that a surgeon experienced in schwannomatosis care be involved to ensure the best possible outcome.

In patients for whom surgical removal of tumors isn't possible, or if pain persists, pain management is usually an integral part of care. Patients are best served in an NF clinic where multidisciplinary specialists experienced in schwannomatosis can administer pain management protocols that have been shown to be effective for people with this condition.

### Finding the Right Specialists

Because schwannomatosis is a rare genetic disorder, it can be challenging to find a specialist with experience in diagnosing and managing the condition. If you have a confirmed or suspected diagnosis of schwannomatosis, it's important to look for a trusted, experienced clinician in your region. Typically, experienced specialists can be found in most major cities. For help in locating a specialist, the Children's Tumor Foundation website, [ctf.org](http://ctf.org), provides a list of specialists within the United States.



“There are many challenges when living with an uncommon condition like schwannomatosis. It is hard to know what limitations exist because of the condition, and how to shape your life around them. However, because there is so little known about the condition, the limitations are left for us to define. Often, the only way to know whether your schwannomatosis will impact something you want to do is to give it a try. Fifteen years ago, I decided to participate in a half-IRONMAN triathlon to set a goal for my recovery from my first surgery to remove a schwannoma. Seven surgeries later, I have surpassed what I ever dreamed was possible – I have completed the last 15 IRONMAN Australia triathlons and finished the IRONMAN World Championship in Kona, Hawaii.”

— **Steve Glowery, endurance athlete who lives with schwannomatosis**

NF clinics provide a comprehensive, multidisciplinary approach to care led by experienced specialists who collaborate in the treatment and management of all forms of NF and its related complications. These specialized clinics also offer access to genetic counselors, nurses, and other caring specialists who can provide patients and families with assistance and support in managing the lifelong medical, psychological, and social implications of an NF diagnosis.

## Sharing the News

One of the most difficult aspects of dealing with a new diagnosis is deciding how and when to tell close friends and family, or even a child who has the condition. Here are some suggestions that may help make the process a little easier.

### WHO TO TELL

This issue is likely to come up when talking with a family member, a close friend, or maybe even a teacher. Many people reveal their diagnosis to others only if it seems important to their relationship.

### WHAT TO TELL

When you decide to share your or your family member's diagnosis with others, you must also decide how much information to share. You might only feel like sharing in a limited way, such as discussing the fact that pain is usually the primary symptom of schwannomatosis. Other times it is helpful to have someone with whom you can share more details, including all of the potential ups and downs that go along with the diagnosis.

### SOME TIPS FOR TELLING CHILDREN

Children prefer routine and certainty. Although schwannomatosis is filled with uncertainty, the more you can establish certain routines and normalcy for the child, the more comfortable he or she will be. It is also important that you tell the truth. Creating a trusting and honest relationship is very important. Keeping a child in the dark can sometimes create more anxiety.

How much you choose to tell your child will vary depending on the child's age and maturity level. Many parents allow the level of information that they tell their child to increase as he or she gets older. This is not a one-time talk, but instead an ongoing conversation that evolves over time. Some studies suggest that until children reach the age of eight, they only need basic information such as the name of the disorder, the parts of the body that are affected, how it will be treated (if at all), and how lives will be affected in the short term.

## SAMPLE MESSAGE TO FRIENDS AND FAMILY

Dear \_\_\_\_\_,

I want to share with you that \_\_\_\_\_ has been diagnosed with schwannomatosis.

Schwannomatosis is a rare genetic disorder that can cause painful tumors, called schwannomas, to grow on spinal and peripheral nerves anywhere in the body. These tumors are usually benign but sometimes need to be surgically removed due to their location or to lessen pain. People with schwannomatosis require special medical care and lifelong monitoring.

Although people are born with the disorder, it may not be diagnosed until adulthood. It is caused by a genetic change and occurs in about 1 in 40,000 births. There is not yet a cure, but scientists and doctors are working toward understanding and treating schwannomatosis.

If you would like to learn more, please visit the Children's Tumor Foundation website at [ctf.org](http://ctf.org).

We appreciate all of your love and support.

Sincerely,

## Connecting with Other Patients and Families

After your diagnosis, you might experience a range of feelings that may include shock, sadness, and uncertainty. While all of these feelings are completely normal, it can be difficult to deal with these emotions by yourself. In addition to getting love and support from friends and family, it can also be helpful to connect with other schwannomatosis patients and families. These individuals might have a special understanding of your thoughts and feelings and offer a uniquely personal perspective about their own experiences and challenges with the disorder. Richard A. Horvitz, an NF advocate and longtime caregiver to his late wife, a schwannomatosis patient, shares his personal insight and advice to others living with the condition.

*“Schwannomatosis is a rare genetic disorder, sometimes initially misdiagnosed and often definitively diagnosed after a prolonged period. Because most people, including many healthcare practitioners, aren’t particularly familiar with it, they often don’t understand the daily struggle that patients encounter with the hallmark symptom of the disorder—pain. This lack of understanding can make patients feel isolated and alone. An invisible yet very real symptom, chronic pain can drastically impact your relationships with other people and your quality of life. Pain is not only distracting in and of itself, but pain medicines and the effect pain has on your sleep can compound the problem. It’s vitally important to remember that the pain you’re experiencing is real—it’s not in your mind—and that garnering support and help from family members and friends is essential. Be assertive about your care, and seek treatment from an experienced specialist who is familiar with the proper surgical techniques for resecting these types of tumors as well as pain management protocols that have been effective for this specific condition, since traditional approaches to pain management are not always as effective. Remember that you are not alone—caring experts and other resources are available to help you and your family navigate this unfamiliar journey together.” — Richard A. Horvitz*



**Richard A. Horvitz,**  
Children's Tumor  
Foundation Board Member



“Our world will forever be changed because of the research that these people do. But we’re not done, far from it . . . we can offer a better tomorrow.”

— Drew Leathers, who lived courageously with schwannomatosis

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## Schwannomatosis Research

### Finding Potential Drug Treatments

The breakthrough discoveries of the *SMARCB1* and *LZTR1* genes associated with schwannomatosis are helping scientists design future studies to test potential drug treatments that target the function of both genes. Other research continues to focus on the discovery of new genes associated with schwannomatosis as well as to explore how the *SMARCB1* and *LZTR1* genes contribute to the condition.

### Advancing Research Initiatives

Since the 2007 identification of the first schwannomatosis-associated gene, *SMARCB1*, the Children’s Tumor Foundation has leveraged this discovery by convening a series of schwannomatosis workshops to identify priorities for advancing research as well as funding schwannomatosis research initiatives. These efforts have yielded the establishment of an International Schwannomatosis Database and collaborative efforts to develop new experimental models for schwannomatosis, and to develop new approaches to treatment. The purpose of the database is to accelerate schwannomatosis research by connecting researchers and patients who have undergone basic screening and expressed a desire to take part in future studies. For more information, visit [schwannomatosis.org](http://schwannomatosis.org).

## Insurance Coverage for Schwannomatosis

Billing and payment for healthcare services in the United States are based on procedure and diagnosis codes. Diagnosis codes are used to determine medical necessity for health services, but the billing and coding processes are quite complex. It is not uncommon for healthcare providers to make unintentional errors that can prompt insurance companies to deny coverage. With patience, you can get insurers to reevaluate these decisions.

Knowing and using the correct diagnostic codes for the various forms of NF helps prevent insurance company errors and mistaken denials. Being proactive and working closely with providers and insurance companies can eliminate most of the hassle and frustration in this process.

Current ICD-10 codes for neurofibromatosis are as follows:

DIAGNOSIS	DIAGNOSIS CODE
NF, type 1	Q85.01
NF, type 2	Q85.02
Schwannomatosis	Q85.03
NF, unspecified	Q85.00

If an insurance company does deny a claim, check with your doctor's office to make sure the claim was fully documented. A lack of information may be the reason why the claim was denied. Make sure that the claim filed includes an NF diagnosis code, the reason for the procedure (e.g., pain, loss of function), and the correct procedural code. If you do not have health insurance, contact your state's Medical Assistance Administration for additional information. Your state government website is a good place to start. Also, check the list of state Medicaid websites maintained by the Centers for Medicare and Medicaid Services ([www.medicaid.gov](http://www.medicaid.gov)). A range of healthcare plans can also be found as part of the Insurance Marketplace. Visit [www.healthcare.gov](http://www.healthcare.gov) for more information on these plans.



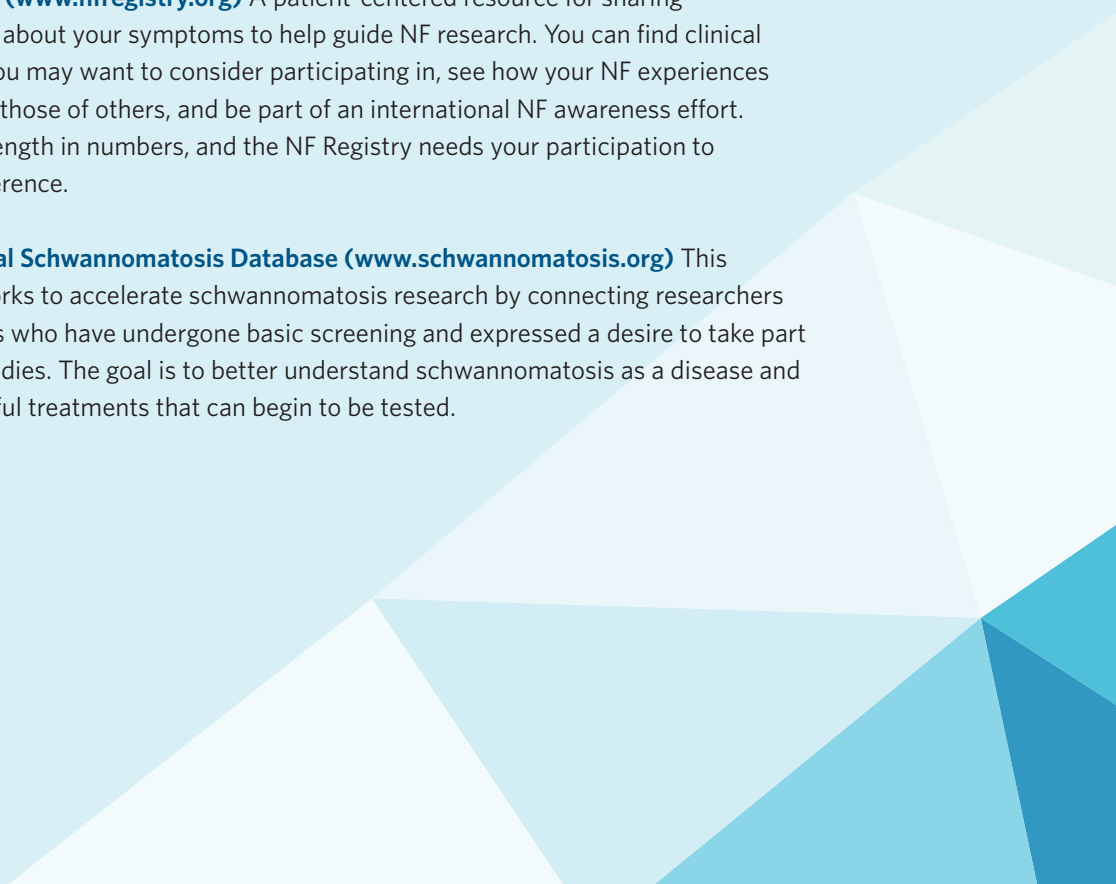
## RESOURCES

Searching for information about schwannomatosis is a positive step that can empower you as a patient. Keep in mind that your doctor is the best resource for information or to answer questions. If you come across any information that you find confusing or strange, it's important that you talk to your doctor.

**Children's Tumor Foundation's website ([www.ctf.org](http://www.ctf.org))** The website of the oldest and largest national foundation for NF in the United States. Here you can find information on NF, support groups, NF specialists, research news, educational events, family events, and many other ways to support the NF community.

**NF Registry ([www.nfregistry.org](http://www.nfregistry.org))** A patient-centered resource for sharing information about your symptoms to help guide NF research. You can find clinical trials that you may want to consider participating in, see how your NF experiences compare to those of others, and be part of an international NF awareness effort. There is strength in numbers, and the NF Registry needs your participation to make a difference.

**International Schwannomatosis Database ([www.schwannomatosis.org](http://www.schwannomatosis.org))** This initiative works to accelerate schwannomatosis research by connecting researchers and patients who have undergone basic screening and expressed a desire to take part in future studies. The goal is to better understand schwannomatosis as a disease and design helpful treatments that can begin to be tested.





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