Facing Neurofibromatosis: A Guide for Teens

by Bruce R. Korf, M.D., Ph.D., Gretchen Schneider, M.S., Diana Platt Frenkel, M.S.

You may have just learned that you have neurofibromatosis, or perhaps you have been going to doctors for years because of the disorder. You may only have minor signs—perhaps just some brown patches on your skin—or you may have been living with more serious complications.

Neurofibromatosis can affect the body in many ways, and it can affect different people in very different ways. In some it may be nothing more than a nuisance, but in others it can cause important medical problems. It is natural to have lots of questions when a person is told that he or she has a condition such as neurofibromatosis. How will this affect my health? Will it change my appearance? Why did it happen? What can be done about it? What should I tell my friends? Can I pass it on to my children? These are important questions; anyone affected with neurofibromatosis should have the facts about the condition. This brochure has been written to explain what is known about neurofibromatosis, and what can be done to help deal with it.

WHAT IS NEUROFIBROMATOSIS?

The term "neurofibromatosis" is put together from two words: "neuro" and "fibroma." "Neuro" means nerve and a "fibroma" is a swelling or bump consisting of fibrous tissue. A neurofibroma is a swelling due to a growth of the cells that surround nerves. Nerves are like wires, carrying instructions from the brain to move muscles, to bring messages back from the body and to convey sensation to the brain. Just like wires, a protective coating surrounds nerves. This coating is made up of cells, and it is the excessive growth of some of these cells that cause the bumps on the skin or under the skin that are neurofibromas. Not all people with neurofibromatosis have neurofibromas that can be easily seen or felt. We will talk about the different ways that neurofibromas can appear later on. Neurofibromas are the most characteristic feature of the condition, though, so that's why the condition bears the name.

There are actually two kinds of neurofibromatosis, called NF1 and NF2. Although they sound like similar conditions, they are in fact quite different. NF1 causes neurofibromas, brown patches on the skin, and a number of other features that will be described later. NF2 causes a different kind of swelling involving the nerve sheath, called schwannoma. Schwannomas occur often around the nerve for hearing and balance: the acoustic nerve. So NF2 really doesn't cause neurofibromatosis at all, although it used to be thought that it did. NF1 and NF2 generally do not happen in the same person, or even in the same family, and NF1 does not turn into NF2. They are totally separate conditions. NF1 is far more common than NF2. Because it is more common, this brochure will be devoted to NF1; if you have NF2, a separate brochure is available with information about that condition.

NF1 sometimes is referred to as "von Recklinghausen neurofibromatosis," in honor of the German physician who accurately described the condition in 1882. It is also sometimes called "peripheral NF," because it tends to affect the peripheral nervous system (nerves), more than the central nervous system (brain and spinal cord).

HOW IS NEUROFIBROMATOSIS DIAGNOSED?

There is no medical test available to definitively diagnose neurofibromatosis. The only way to tell that a person is affected is to examine him or her to see if there are signs of the disorder. There are several features that your doctor will look for, and it is generally agreed that anyone having at least two of the features on this list has NF1.

Diagnostic Features of Neurofibromatosis

- 6 or more cafe-au-lait spots
- freckling under the arms or in the groin
- 2 or more neurofibromas
- Lisch nodules (tiny, tan bumps) on the iris of the eye
- optic nerve tumor (optic glioma)
- characteristic bone abnormality
- family history of NF1

Cafe-au-lait spots are flat, brown patches on the skin. The term "cafe-au-lait" comes from the French term for "coffee with milk" because this is similar to the color of these skin spots. They usually begin to appear during the first year of life, and continue to increase in number for at least the first few years. It is not unusual for anyone to have one or two cafe-au-lait spots, but most persons with NF1 have a large number, generally more than 6. There is no connection, though, between the number of cafe-au-lait spots on a person with NF1 and the severity of the condition, or between the location of a cafe-au-lait spot and the location of a neurofibroma. Cafe-au-lait spots may tan during the summer on exposure to sunlight and will fade in winter. Too much exposure to sunlight is not good for any one's skin, but the tanning of the cafe-au-lait spots will not cause any harm. In general, the cafe-au-lait spots, are harmless, and serve only as a clue that someone has NF1. They sometimes fade later in life, but we will talk later about ways of treating them if their appearance is a problem.

Another characteristic skin feature is freckling under the arms or in the groin. Most people only get freckles in parts of the body exposed to sunlight, whereas those with NF1 get the freckles in non-sun exposed areas as well. These freckles are harmless, but can help make the diagnosis of neurofibromatosis.

We have already talked about the neurofibroma, that it represents a growth of the cells that made up the coverings surrounding nerves. Usually neurofibromas are noticed as a small bump on the skin, often like a mosquito bite that doesn't go away. Sometimes there is a little pinkish or purplish color over the site of a neurofibroma. Most skin neurofibromas are small, from pinpoint sized to the size of a pencil eraser. They can occur anywhere on the skin, and can appear at any time in life There is no telling how many neurofibromas a person with NF1 will get: some people just get one or two, but others get many more. We'll consider the cosmetic effects and what can be done about this a little later.

Neurofibromas can occur not only on the skin, but also any place in the body where there are nerves. Sometimes neurofibromas can be felt as pea-sized or larger humps under the skin. Others may be so deep in the body that you will not know that they are there. Skin neurofibromas are usually soft and painless. Those that are under the skin are firmer in consistency, but are also usually painless. Sometimes, however, if a neurofibroma puts pressure on a nerve, symptoms will develop. These can include pain, numbness of a part of the body, or weakness. If you experience any of these problems you should tell your doctor.

One particular kind of neurofibroma deserves special mention. This is the plexiform neurofibroma. Plexiform neurofibromas represent growths around large nerves. They are thought to grow while a person is developing as an embryo, so they are usually present at birth. Sometimes they will be obvious early in life as an area of swelling, but other times they can be deep inside the body and harder to detect. When they are present near the surface, they sometimes grow to rather large site and cause deformities. Usually, if this is going to happen, it happens in the first few years of life. If these large neurofibromas are not present by adolescence it is unlikely that they will ever appear.

Lisch nodules are tiny, tan humps on the iris of the eye found in most people with neurofibromatosis. They are totally harmless, and never cause pain or problems with vision. They are hard to see without a special lens called a "slit lamp," used by an eye doctor (ophthalmologist). This can be a very helpful diagnostic sign of neurofibromatosis.

Another feature of neurofibromatosis that can affect the eye is optic glioma. Optic glioma is a growth that involves the cells of the optic nerve, the nerve that connects that eye to the brain. Most of the time this does not do any harm, but in some cases it can cause problems with vision or with the production of hormones. Optic glooms are usually diagnosed by doing a scan such as MRI (this stands for magnetic resonance imaging, which takes a picture of the brain or other parts of the body.) Optic glooms that cause problems usually do so in young children between 4 and 6 years old. It would be unusual for problems to first appear much after this time.

Two problems with bone development can be characteristic of neurofibromatosis- and help in making the diagnosis. One is curvature of long bones, especially the tibia (shinbone). This is generally present at birth, and will not appear later in life if it is not present at birth. When it occurs, it can cause weakening—and even fracture—of the bone. It will not occur out of the blue in a person with NF1 who does not have the problem at birth.

The second bone abnormality of NF1 involves the bones that surround the eye—the orbit. Rarely, these bones will be malformed, usually with neurofibroma growth behind the eye and involving the upper eyelid. This can have major cosmetic effects, but, fortunately, it is rare. Also, this problem would be present right from birth, and will not develop all of a sudden in an older person with NF1.

The final diagnostic criterion is the presence of NF1 in a parent, sibling or child. As will be discussed later, NF1 is a hereditary condition, so its presence in a relative can be a clue to help make the diagnosis in a person who may have only a few signs. Anyone who has any two of the features mentioned above is said to have NF1. One of the difficulties in diagnosis, however, is the fact that some of these features are not found in young children, and only appear later in life. This applies particularly to freckling, neurofibromas and Lisch nodules. Often, the first sign of NF1 is the appearance of cafe-au-lait spots, while other features only appear later on. That is why it is often necessary to examine a

child year after year in order to confirm that he or she really is affected with neurofibromatosis.

HOW DOES NF1 AFFECT THE BODY AND WHAT CAN BE DONE ABOUT IT?
Many of the effects of NF1 have already been mentioned: cafe-au-lait spots, neurofibromas, etc. There is a long list of things that can happen as a result of NF1, but it is important to remember that no one gets them all, and most of the severe complications are fairly rare. We estimate at least 2/3 of those with NF1 have the disorder in a mild form. What's more, some of the more severe complications, like plexiform neurofibroma or optic glioma, would already be present by early childhood if they were going to happen at all. A teen that does not have these complications has already escaped some of the more serious problems of the disorder. On the other hand, part of dealing with NF1 is realizing that no two people with the disorder, even in the same family, seem to be affected in the same way, and the condition is unpredictable.

COSMETIC EFFECTS
Some people with NF1 have no change in appearance due to the disorder, but it is common to have at least some features that are visible on the skin, Cafe-au-lait spots may be the most obvious skin change in most young people with NF1. Usually, these do not increase in number after the first five or so year of life. Sometimes they can be covered with clothing, or, if present in an obvious area, with makeup. Actually, it is not that common to have cafe-au-lait spots on the face. It is possible to have cafe-au-lait spots "removed" by treatment with a special laser. It would not be practical to do this for every spot, but a particular cafe-au-lait spot that is especially bothersome could be removed by this method.

Skin neurofibromas, when present, may cause more obvious cosmetic effects. A single neurofibroma can be removed by surgery, although there is no guarantee that the neurofibroma will not grow back. Usually, surgical removal of neurofibromas is reserved for a particular skin bump that is in an obvious place and is unsightly, or is located at a spot where it causes discomfort, for example, rubbing against clothing. Some people with a large number of neurofibromas have chosen to have many removed at the same time, sometimes dozens or even hundreds. There have been claims of successful removal of neurofibromas using a special kind of laser. This is an expensive procedure, and it has not yet been shown to have a lasting effect on improving appearance in people with neurofibromatosis. You should ask your doctor if you have questions about this method of treatment.

The most severe cosmetic effects of neurofibromatosis result from the growth of plexiform neurofibromas around the eye or on the arms, legs or trunk. As was mentioned earlier, this kind of problem first appears in very young children, so if a teenager does not already have a large plexiform neurofibromas, it is very unlikely that he or she will ever have one. On the other hand, if you do have one of these plexiform neurofibromas, you know they can be difficult to deal with. The only treatment available so far is surgery, and it is common to require many surgical procedures in order to remove some of the neurofibroma and try to improve appearance. Unfortunately, there is no way to completely remove a plexiform neurofibroma because its "roots" extend too deep. Therefore, they have a tendency to grow back after surgery. On the other hand, plexiform neurofibromas may grow for a while, and then stop growing on their own. So far there is no way to stop the growth of plexiform neurofibromas using medication, but this is a major area of research, to be described later.

PAIN

Fortunately, neurofibromas are not usually painful. Sometimes, a neurofibroma may become painful if it is bumped, and that pain can last several days in some cases. This pain generally goes away, though. Neurofibromas located under the skin can cause a tingling or shock-like sensation if pushed on. Only rarely does the pain become severe enough to require treatment. Sometimes, the best treatment is to remove the neurofibroma, but this is not always possible. If the neurofibroma cannot be safely removed, there are other methods of treatment available that can be very helpful. You should talk with your doctor about any neurofibromas that are painful, so that a careful examination can be done and appropriate treatment offered.

GROWTH AND DEVELOPMENT

Some people with NF1 find themselves to be a few inches shorter than others of their age, and than others in their families. This seems to be a common pattern of growth in NF1, and the reason for it is unknown. As long as growth is occurring at a consistent rate, there is nothing to worry about medically. Hormone treatments have been used to stimulate growth if it is occurring very slowly, but that usually does not need to be done. Likewise, many with NF1 have slightly larger heads than other people. This may become apparent when trying to fit a hat, or a helmet. Head size in NF1 has no relationship to intelligence.

Puberty is a time of many body changes, and these usually occur normally in people with NF1. Occasionally, however, these changes will begin earlier or later than usual. Your doctor will be looking out for this, and may suggest some medical tests to find a reason for early or late puberty if it occurs. This can usually be treated with hormonal therapy. You may have heard that puberty tends to bring out more neurofibromas. It is often the case that neurofibromas first appear during the teen years, or may grow at that time.

The cause for this is not known. However, it is important to realize that not everyone with NF1 experiences a change in his or her neurofibromas at this time.

LEARNING DISABILITIES

A large number of people with NF1 seem to have some difficulty with learning. Learning disabilities are actually common in all people, with or without NF1, but may be more common in those with NF1. Having a learning disability does not mean that a person is not intelligent. Learning disability means that a person has trouble with some particular aspect of learning new knowledge. This can take many forms. Some have trouble paying attention, or remembering a sequence of instructions. Some have difficulty reading, or doing math. The particular kind of learning disability varies from person to person with NF1, and also varies in severity. Only rarely is there significant impairment of intelligence due to NF1. Also, it is important to realize that learning disabilities generally do not get worse over the course of time.

It is very important to recognize learning disabilities and to take steps to deal with them as soon as possible. Unfortunately some children with learning disabilities are misunderstood in school, and thought to have bad behavior, or not be working hard enough. Some teachers and parents may push to have the child work harder, not realizing that the child is working as hard as he or she can, but may be unable to perform certain tasks in school as well as others. When special help is given, a learning-disabled person can often do very well in school. Persons with NF1 can go to college and hold any kind of job. Fortunately, awareness about learning disabilities in general, and in association with NF1 is increasing and it is getting easier to arrange for special help for those who need it.

IS NEUROFIBROMATOSIS A FORM OF CANCER?

Neurofibromatosis is not a form of cancer, and neurofibromas are not cancerous tumors. Cancer is a disease in which some of the cells of the body grow in an uncontrolled manner, and then spread throughout the body.

Neurofibromas do tend to grow, but they do not grow like a malignant (cancerous) tumor and they do not spread. You may have heard that neurofibromas sometimes can become malignant, or that other malignant tumors, like brain tumors, can occur in neurofibromatosis. It is true that this can happen, but fortunately, it is rare. The lifetime risk of a malignant growth related to neurofibromatosis is about 5%, or one out of twenty. This may seem like a high risk, but is must be remembered that about 25%, or one in four persons in the general population—who do not have NF— will get a cancer sometime in their lives. Neurofibromatosis, therefore, adds only a little to the risk that all persons face of developing cancer.

The skin neurofibromas almost never become malignant. It seems to be the plexiform neurofibromas that are at risk of becoming malignant. The signs of malignancy would be sudden growth of a neurofibroma that was either not growing before, or was only growing slowly, and the appearance of unexplained pain in a neurofibroma. Pain that occurs in a neurofibroma after it is bumped is not worrisome, but if the pain appears for no apparent reason and does not go away, that should be checked out.

MEDICAL FOLLOW-UP FOR NF1

You should expect to live a long life and enjoy good health in spite of having neurofibromatosis. NF1 can cause life-threatening problems, but fortunately these are rare. The majority of people who have NF1 go through life with relatively few medical problems related to the disorder, and enjoy good general health. It is important to have regular medical follow-up, in order to catch any complication of the disorder as early as possible.

Generally, it is a good idea, to see a doctor who is familiar with the disorder at least once a year, or more often if a particular problem is recognized. This doctor can be your family doctor or may be a specialist who deals specifically with neurofibromatosis. You should use these visits to ask any questions you might have about the condition, and to call attention to any changes you have noticed in your body. It is especially important to ask about problems such as pain, growth of neurofibromas, or headaches. Usually, your doctor will be able to reassure you with a simple physical examination. Sometimes special tests will be done to check out any symptoms you may be experiencing. This is important in order to catch problems as early as possible.

IS IT NECESSARY TO LIMIT ACTIVITIES DUE TO NEUROFIBROMATOSIS?

Just having neurofibromatosis does not mean that you should limit your normal activities in any way. People with neurofibromatosis are not especially fragile or prone to injury. Of course, if you have a particular complication of neurofibromatosis, such as a problem with the shinbone or spine, this may require special protection and can interfere with some physical activities. You should ask your doctor if you are in doubt about this.

GENETICS OF NEUROFIBROMATOSIS

Neurofibromatosis is caused by an abnormality in a gene. Genes are tiny structures inside our cells that control our growth and development. Genes determine traits such as hair color, how tall we are, our blood type, etc. Most of our genes come in pairs, we inherit one from our mother and one from our father. This explains why we tend to have

traits similar to our parents. A change in a gene that prevents it from functioning properly may result in an altered trait or in a genetic condition. Neurofibromatosis is such a condition. It is inherited as a dominant trait, which means that in an affected individual only one gene of a particular pair has been changed. A person with a dominant condition like NF has a 50% chance of passing the abnormal gene to each of his or her children.

Many people with NF wonder why they are the only ones in their family who seem to be affected if NF is a heredity condition. Someone with NF can get the condition in one of two ways. First, they may have received the NF gene from one of their parents, who also has the condition. Often it is clear which parent has NF and there may even be others affected further back in the family. Other times, a parent may be mildly affected, and be unaware of having NF until a medical examination is done.

Approximately 50% of children diagnosed with NF have received the gene from an affected parent. The other 50% get NF as the result of what is referred to as a “new mutation”. In these people, neither parent is affected and the gene change resulting in NF occurred for the first time in the egg or the sperm that produced the infected individual. Although parents often worry that they may have done something to cause such a mutation, we know that this is not the case. Since passing on our genetic material is such a complicated process, it is not uncommon for changes to occur by chance, and result in a condition like NF.

Although a person who has inherited the NF gene from a parent is no different form one who has a new mutation, it is important to determine how the change arose since this may have implications for other people in the family. It is usually fairly easy to decide if a parent is affected by looking for signs of NF such as café-au-lait spots and neurofibromas and looking at the eyes for Lisch nodules. If none of these are found it is very unlikely that a parent has NF. This is important because it means that the risk to brothers and sisters of someone with NF is very law. It is important to remember, however, that regardless of whether a person received the NF gene from a parent or by new mutation, he or she has a 50 % risk of having a child with the same condition. It may seem a long way off, but it will be important to consider genetic implications of having NF as you get to an age where you start to plan a family of your own. People with NF are usually able to have children, in spite of this 50-50 risk that a child will inherit the disorder. Recent advances in understanding the genetics of NF make it possible in some instances to determine if a baby has inherited the NF gene. Unfortunately, though, there is no way to predict how severe a child might be affected. In some cases, mildly affected parents have children with severe complications of NF. When the time comes, it will be important for you to discuss the genetics of NF with your partner, and speak with your doctor to learn the most up-to-date information about NF and what can be done about it.

DEALING WITH NEUROFIBROMATOSIS

Adolescence can be a difficult time of life. It is a period when you are in between being a child and an adult, growing both physically and mentally. It is also a time when you are trying to figure out who you are and what you believe in. This can cause your feelings and emotions to intensify. You may feel confused, out of control, or think that nobody understands you. Having NF may add to these emotions and can make an already stressful period seem even more so.

NF can cause a number of physical changes to occur during adolescence. This can be difficult because it is a time when you usually become more aware of your body. Outwardly visible cafe-au-lait spots or neurofibromas may have already made you wrestle with being "different" from others. During puberty, neurofibromas may grow

larger, become more visible, or increase in number. This may call attention to them, make others more aware that you have NF, and may intensify your feelings about NR Being more self-conscious about your body can make changing during gym class or sleeping over at a Friend's house feel particularly awkward. In addition, having NF can hasten or delay the onset of puberty in some cases. If this happens, you may feel uncomfortable about physically maturing before or after your peers.

Adolescence is also a time of change in your relationships with your family. It is natural for teens to want more control over their lives and to make more of their own decisions. But, adolescence is also a time during which changes in the manifestations of your NF can occur. Your parents are aware that you might develop more signs of NF during this time and they are, naturally, watchful and concerned. This can intensify the tensions of adolescence as teens sometimes resent the scrutiny of their parents and want more independence. But, this can also be a lonely and frightening time for you, feeling anxious about the changes that might occur. You need the support of your parents. It is important for parents and teen to make extra efforts to communicate with each other during this stressful time. Both parents and teens do well to remember that listening to one another is an essential part of communication. Slow down and let your parents speak, and ask them to hear what you need to say as well. Parents and teens can work together as a team to handle what comes during adolescence and to manage NF.

At times you may feel angry and out of control about having NF, since there is nothing you can do to prevent these changes from occurring, ft is important to remember that other adolescents experience similar feelings for different reasons. Most adolescents dread "standing out in a crowd" or being different from everybody else. The truth is that no two people are exactly alike, and everybody has something that makes them different, NF may be just another difference for you.

During adolescence, you may begin to be more involved in your own medical care. At the same time, doctor's visits will probably be difficult for you. You may not to share information about your body or about changes that have occurred. You may think of it as an invasion of privacy. This is a common reaction for teens, whether or not they have NF. It is important to realize, however, that seeing a doctor on a regular basis can help to keep an eye on changes that may need medical attention, as well as give you an opportunity to learn more about NF from your doctor.

Having NF can sometimes make you feel alone and isolated. If you are the first person in your family to have NF it can be especially hard. You may not understand how it occurred. Even if NF runs in your family it may be difficult to talk with family members about it. You may wonder why you were "chosen" rather than a brother or sister, or you may feel uncomfortable if you have to go to the doctor more frequently. You also may not know any other people your age with NF. In any case, you may think that no one could possibly know how you feel, or how it feels to have NF. You should remember that you are not alone in your experiences. There are many people of all ages with NF, and it may be helpful to contact your local NF chapter or your doctor about finding other people with NF to talk to.

Deciding to tell people that you have NF can be very difficult. Whether you have a few visible signs and no one knows you are affected or if your NF is more obvious, having NF is a very personal matter and whom you share this information with is your choice. You may want to tell your friends in order to bring you closer, yet even the closest friends may ask difficult questions. They may make you feel vulnerable, or treat you differently. They may wonder about those "things" on your skin. They may not understand what a

genetic disorder is, and be paranoid about "catching" NF. You shouldn't divulge information unless you feel comfortable in doing so. If you do decide to share with them, you may be able to teach them something about genetics and NF, and this may help them to understand your situation better.

It is helpful to rehearse (ahead of time) responses that you might want to give, so that you are not caught off guard. With acquaintances that ask about cafe-au-lait spots or neurofibromas, for example, you might want to give a very brief answer such as, "It's like a birthmark," or "It's just a little skin problem." With closer friends, you might choose to explain more about the genetic condition. There are some terms, such as "tumor," that have unnecessary connotations and you might want to choose not to use them in your explanations to peers.

Telling your teachers about NF can be another hard decision. The most important reason for them to know is if you nave learning difficulties and need some special help. Another reason to tell teachers you have NF is that it may help to educate them and perhaps others in your school about NF, and correct any misconceptions about the condition. At the same time, many people don't want to tell their teachers they have NF because they are doing fine and are worried that they will be treated differently. Talking about this with your parents and discussing you concerns may help in making the decision that is best for you.

As you gain more information, you may begin to think about the future implications of having NF. Questions about NF limiting career choice or causing medical complications may occur. You might also begin to consider the possible effects of NF on your decision to have children. Talking with your doctor and your parents may help to address some of your concerns and relieve your anxieties. There is considerable uncertainty with NF and this can be overwhelming at times. Take it one step at a time and do not worry about decisions too far in advance. As you move closer to adulthood, you will want to become as well informed as you can about NF and your options. Local chapters of the Children's Tumor Foundation may offer lectures, written information, a website, and support groups, which can be very helpful. Many people find that becoming more involved helps them to learn more and feel more in control of their condition.

It is important to remember that all people have some kind of adversity to deal with in their lives. NF is a challenge, but the process of accepting it as part of yourself can make you a stronger and more understanding person. It is normal to feel angry and overwhelmed at times as you face the challenged of NF. However, when you take an active role in dealing with NF, as opposed to simply enduring it passively, you feel better about yourself and turn your adversity into some kind of positive growth experience. Taking more responsibility for medical care is one way that teens can deal with NF in a more active manner. Talking to others with the condition, joining an NF support group, or becoming involved in educating others or fund-raising for NF research can give you a feeling of strength in the face of your difficulty and lessen your feelings of being different. It is also Important to remember that NF may be one part of you, but it is only a small portion of who you are. Find activities in which you can excel. Feeling competent and getting positive feedback will increase your self-confidence and help you to put your NF in perspective. There is so much more that you can do than not do. You still have to go through the same things as all of your friends without NF. Feeling better about yourself and having a positive attitude will help you to deal with having NF, as well as life's everyday problems.

WHAT KIND OF RESEARCH IS BEING DONE ON NEUROFIBROMATOSIS?

There is currently no way to prevent or reverse the complications of neurofibromatosis, and there is no diagnostic test for the condition. This is a time of great hope, though, that new methods of treatment will be developed through research. The genes, responsible for NF1 and NF2 have been identified and are being studied by scientists all over the world. For the first time in the more than one hundred years since NF1 was carefully described, we have the tools necessary to understand what is really going on in this disorder. This has already changed the way that we diagnose neurofibromatosis in some cases- The ultimate hope is that we will understand the normal role of the neurofibromatosis gene, and find out how to control its function. There is no way of knowing when or how this will result in a cure, but you can expect exciting progress to come faster and faster in the next few years.

CONCLUSION

NF is a life-long condition, and you must learn to live your life, and not let the disorder rule your life. The more you understand the more you will be in control, so be sure to ask questions of your parents, teachers, and medical professionals. Find someone you trust, and share your feelings, fears and frustrations. The challenges posed by having NF are hard, but they can be overcome.

To find out about local chapters and/or support groups in your area, call the Children's Tumor Foundation at (800) 323-7938 or log on to the Foundation's website at www.ctf.org.

* * * *

We gratefully acknowledge the assistance of Dr.Helen Hand, Ph.D , a clinical psychologist who contributed her expertise and insight to the writing of this guide

ADDITIONAL INFORMATION

The Children's Tumor Foundation can be a source of educational materials and support. They can be reached at:

The Children's Tumor Foundation
95 Pine Street, 16th Floor
New York, NY 10005
212-344-6633 or 1-800-323-7938
Email: Info@ctf.org
Internet: www.ctf.org