

The Tremoractionorg Newsletter

OCTOBER 2001

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WELCOME TO THE OCTOBER ISSUE!

October is National Movement Disorders Awareness Month! Tremor Action Network requests your participation to increase community awareness about movement disorders.

Romert and movement disorders awareness friends extend an invitation to visit Tremor Action Network at the following October Awareness events.

Dome Arena: Thursday, October 4

18th Annual Family Health and Fitness Fair

http://www.domecenter.com/

11:00am - 5:00pm

Table 42

2695 East Henrietta Road

Henrietta, NY

St. Rose Hospital: Sunday, October 7

6th Annual Health Faire

10:00am - 2:00pm

27200 Calaroga Avenue

Hayward, CA

Auburn Holiday Inn: Saturday, October 13

10th Annual Women's Health Institute

http://www.auburnhospital.com/amh/files/flyer7.pdf

8:30am - 2:00pm

75 North Street

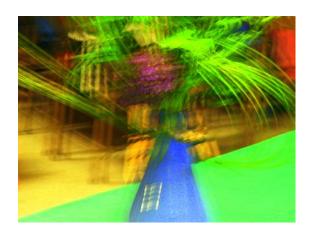
Auburn, NY

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Some Thoughts about Photography and Tremors

By Mona Reeva, PhD, MPH, LCSW

Last year I showed a projected pictorial image of a floral bouquet in a beautiful blue vase in the creative section at my camera club, which brought many laughs, although sadly enough, no awards. I called the image, Shaking Bouquet. It was as if there were several images fanning out from the center. Very colorful and bright. A friend asked me how I did it - I said it was simple - I just let my hands shake while I took it - sort of au natural! Well, we both laughed.



For those of us who enjoy taking photos, either new to the process or long timers, when the tremor starts impacting this wonderful hobby or profession, there are ways we can still continue to work. These methods or tricks aid us in dealing with tremors and allow us to maintain our interest and desire to continue to shoot images. I think it is important to accept the problem as a challenge and make our adaptation to this new or long-standing development. Not easy and I don't want to give such an impression. Sometimes it can be a miserable struggle. And after a series of images in a particular set come out as unusable it can be frustrating and despairing. Remember though, that those with steady hands sometimes do the same - get a set of photos that need to be discarded. Since more of us are using digital cameras, the expense of developing and finding unusable images is not the same. It is, however, always disappointing.

I want to share with you some of the tools I use that help me in my pursuit of sharp images that make the photo look great. One of the most important tools is to have a camera and or lenses that include IS - image stabilization. While I'm referring primarily to digital as that is all I use now, this is also true of film cameras. Some cameras have IS in the body of the camera and for some single lens reflexes, it may be part of the lens. Three types of cameras at our disposal are point and shoot, bridge and single lens reflex. If you are using a camera without IS, and are considering upgrading, this would be a very useful tool to have.

One of the tricks I have is to use stabilizing objects that I can either place the camera on, or use to lean against. For example, if I am taking macro shots out in the field and want a close up of some flowers or insects close to the ground, I might find a rock or stone to place my camera on, or lean it against in order to stabilize my hands. When I recently took aerial photos of San Francisco, I was in a very tall building on a terrace overlooking the city and I held the camera on the stone railing as I shot.

Recently I acquired a small "guerilla" tripod that can wrap around objects so that the camera is stabilized. This can be placed on uneven objects that will allow you to take the photo in difficult terrain and in unusual positions. In terms of tripods as there are many on the market, what seems important to me is to ask friends, talk to people knowledgeable about tripods, look on the internet and see and feel them with your camera screwed on and see which one feels the most comfortable for you. While a tripod and a cable release are not usually useful if you are taking spontaneous shots, they are useful for more planned shooting.

While some of the new cameras do not have a place to connect a cable release on the camera, most do have time delay release which can be set for varying seconds of delay; others may have a socket where you can connect an external shutter release. These can eliminate the shaking finger for certain kinds of shots. Thus no need to use tremoring hands and or arms. Obviously these also are not

for spontaneous shooting, but do work under certain conditions.

Many of the newer cameras have larger LCD screens useful for positioning your subject in subdued light. If you are in bright sunlight a viewfinder is easier to use. With most of the newer point and shoots, though, the viewfinder has been eliminated. When I bought my recent point and shoot to carry with me I looked for one with a viewfinder as well as a high number of megapixels. In using the new camera, I have become more used to shooting while looking at the screen when possible as I can hold my arms out and steady myself more easily. When I use the viewfinder I like to lean against something to aid with stabilizing my arms and hands.

In the meantime, let's enjoy what we love to do. I encourage those of you who haven't yet picked up a digital camera to do so, and for those of you who love this art, to continue to take pictures. As we are all aware, engaging in positive and productive activities that feel good is good for our mental health.

Also, there are harnesses that you can wear around your back and push against in front of you to assist in stabilizing your hands and thus the camera.

I tend to use lightweight cameras, although I have read that some people with tremoring hands like heavyweight

ones to help them stabilize their cameras. I find I can't hold the heavier cameras without inducing additional shakiness so I like the lightweights better. Again this is so individual and requires research about different kinds of cameras and making the decision regarding which is best for you.

One of my fears is that my tremors will increase to the point that I can't stabilize my hands sufficiently to still enjoy the art of photography. I think that if that happens, I know I will feel a great loss.

Perhaps newer devices will be invented, or perhaps some may already exist that I don't know about. If you know of such devices or other methods that I haven't mentioned, please let me know so I can pass this along to others in a future article. I would like to hear from you.

"Engaging in positive and productive activities that feel good is good for our mental health"

About the Author

Dr. Mona Reeva writes a quarterly column that focuses on mental health issues. Readers are invited to ask questions that will be answered and featured in subsequent newsletters.

A member of the Tremor Action Network online support group started a discussion thread, Looking for Amateur Photographers with Tremor. TAN turned to Mona for assistance because of her award winning photos at http://www.flickr.com/photos/drmona/.

TAN's new photo slide show located on the organization's website is courtesy of Mona Reeva, PhD. All Original Photos © Copyright, M Reeva.

Simpson conquers various ailments to return to the links

By Ron Kroichick, Chronicle Staff Writer

Spikes & Spasms Note:

This article, courtesy of the **San Francisco Chronicle**, the Northern California newspaper founded in 1865, appeared on page C-2 of the San Francisco Chronicle **Sporting Green** on Sunday, September 2, 2007. Tremor Action Network is grateful to Ron Kroichick, Glen Schwartz, Sports Editor, and the San Francisco Chronicle for granting permission to reprint the article for viewing only.

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PEBBLE BEACH - Tim Simpson once tangled with the elite. Among his four PGA Tour victories was the 1989 USF&G Classic in New Orleans, where he trailed Greg Norman, then the world's No. 1 player, by one shot entering the final round. They were paired together in the last group - and Simpson shot 69, to Norman's 72, to win by two.

And then, as Norman spent the next several years in perpetual contention in tournaments around the globe, Simpson started his slow descent into misery. He contracted Lyme disease in 1991, initiating a 14-year medical odyssey that would include spinal fusion surgery, triple hernia surgery, four eye surgeries and, ultimately, life-changing brain surgery.

"I'm really a walking miracle," Simpson said.

He spoke those words Friday at Pebble Beach, on the inaugural day of the First Tee Open. Nearby, sunshine draped the storied links and sparkled on the waters of Carmel Bay. A few hours later, Simpson hopped over to Del Monte and shot 2-under 70 in the opening round of the Champions Tour event pairing 50-and-older professionals with promising juniors.

In other words, Simpson, 51, practically has come full circle since his heady, healthy days on the PGA Tour. He finished sixth on the money list in 1989 and eighth in 1990. At one point, he climbed inside the top 20 in the world rankings, a consummate ball striker surging in his mid-30s.

But on a hunting trip in his native Georgia soon after the 1991 Masters, Simpson woke up to the jarring sight of hundreds of deer ticks on his chest. Doctors eventually diagnosed him with Lyme disease, an infectious disease that causes Simpson chronic joint stiffness to this day.

His physical problems grew worse in the mid-1990s, when his left hand began to shake uncontrollably at times. Simpson kept playing, even as he fell to what is now known as the Nationwide Tour, but the shaking obviously hurt his game and sent him spiraling into frustration.

The condition was later diagnosed as "benign essential tremors," an ailment leading to Parkinson's-like shaking when Simpson put his left hand in certain positions - such as gripping a golf club.

"It was a living hell," he said. "The most successful professional athletes are Type A control freaks. If you're hitting it bad, you pound balls for five hours. If you're putting it bad, you practice putting for five hours. When you lose control, you don't know how to deal with it.

"It was tough. I missed out on 10 to 15 years of my career, in my prime."

Now, in retrospect, Simpson said he probably should have retired in 1992. But he was only 36 then, a muscular former high school quarterback accustomed to playing in pain. So he stayed with it until 1998, when he finally quit golf. He plunged into depression and got divorced, his career and personal life in shambles.

Even after Simpson met his second wife, Leigh Anne, in 2000, he still wanted no part of the game.

"It was very depressing to him, because he was pretty much on top of the world at one time," Leigh Anne Simpson said. "He didn't pick up a club and he didn't want to talk about golf. He was so down those years."

Simpson returned to the Nationwide Tour in 2004 and hit the ball well in the first tournament of 2005, in Panama - but still missed the cut, because his shaky left hand failed him around the greens. That's when he decided to try deep brain stimulation, a surgery approved only eight years earlier.

The operation carried enough risk that Simpson wrote a letter to family members and close friends, asking them

not to be sad if he died. He had lived a great life, he wrote, even if his career ended prematurely.

But the surgery went extraordinarily well. Doctors placed a halo-like contraption on Simpson's head, strapped him to the operating table and spent nine hours working to successfully implant an electrode in his

brain and a battery-operated device - often called a pacemaker for the brain - in his chest.

Once the device was activated, Simpson (who was awake during the surgery) felt a sharp electric surge down his left arm and leg.

And the shaking in his hand stopped.

"That's when all hell broke loose in the operating room," he said. "It was unbelievable excitement. They knew they got it in precisely the right spot."

Two-plus years later, Simpson resembles a modern-day bionic man. He sports a visible bump on the right side of his balding head, where there's literally a hole in his skull. The wire inside his skin runs across his scalp, down the left side of his neck and snakes around to reach the device

implanted in his chest.

Simpson's day-to-day life is back to normal, essentially. His golf game also is coming along: He earned Comeback Player-of-the-Year honors on the Champions Tour last year, when he won nearly \$360,000 and finished 46th on the money list. Simpson stands No. 34 this year, giving him a chance to qualify for the season-ending Schwab Cup Championship in Sonoma (province of the top 30).

That's a tantalizing bonus for a once-gruff, since-mellowed man who wondered if he would ever play competitive golf again.

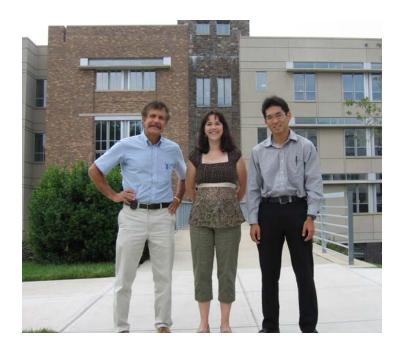
"I appreciate every day out here," Simpson said. "I really do."

E-mail Ron Kroichick at rkroichick@sfchronicle.com.

"Two-plus years later, Simpson resembles a modern-day bionic man."

About the Author

Ron Kroichick is an award-winning sportswriter for the San Francisco Chronicle. He joined The Chronicle in 1995, after eight years at The Sacramento Bee. Kroichick covers golf and writes in-depth stories on a variety of topics, including major-league baseball, the NFL and sports business issues. His work also has appeared in ESPN Magazine, The Sporting News and Diablo Magazine.



Duke Center for Human Genetics

By Hokuto Morita

Tremor Action Network (TAN) visited the Center for Human Genetics at Duke University in July to learn more about the Center's essential tremor (ET) genetics studies. The ET genetics program at Duke is currently being led by researchers Allison Ashley-Koch, PhD, and Jeff Stajich, PA.

The Center for Human Genetics (CHG) is a "state of the art" facility dedicated solely to the study of the genetics of human disease. Not only does the CHG study ET but also other diseases such as Sickle Cell Disease, Autism, Muscular Dystrophy, Alzheimer's Disease, Parkinson's Disease as well as many others. In fact, the Center for Human Genetics is well known for being the first to identify one of the genetic risk factors for Alzheimer's Disease. There are several reasons why the Center stands apart in its ability to study the genetics of human disease. Dr. Ashley-Koch and Jeff Stajich gave TAN a tour of the facilities and explained some of the advantages that researchers at the Duke CHG have.

Technology: All of the labs in the CHG share core facilities that have the most up-to-date and advanced machinery.

Since the Center has centralized core facilities that all labs in the CHG can utilize, even the smaller labs in the CHG that normally wouldn't have access to advanced facilities elsewhere, have access to the most advanced techniques and equipment. This makes a huge difference, as the automated sample processing allows researchers to handle many more samples in less time than if they were done manually.

Logistics: The CHG has a room with pre-packed travel packages that contain all the supplies needed to travel to distant locations and collect blood samples. This allows Jeff Stajich to instantly pack up and travel to other parts of the country so that families with ET that want to participate in studies but don't live in the North Carolina area can also participate. The CHG also has clinical exam rooms within the facility so that participants don't have to make extra trips to get evaluated or to give blood samples.

Database: The researchers at CHG use a special database called PEDIGENE. PEDIGENE is a program that was created by Duke geneticists specifically to streamline the process of genetic analysis. The software package, currently being used by only Duke University and the University of Miami, allows the geneticist to instantly access the tools and data required for genetic analysis all in one program. In most facilities, this is not the case as data on brain samples, family trees, blood samples, and medical records are often kept in separate databases. Having all the records in one place along with the genetics analysis software speeds up the process of identifying disease associated genes.

Yet even with all these tools, the study of human disorders is incredibly complex. This has been particularly so with the study of ET. According to Dr. Ashley-Koch, the study of ET has been much more complex than she and her team originally anticipated. Initially, since many cases of ET seemed to be inherited in a simple Mendelian fashion, researchers thought that finding a gene linked to ET would be quite simple. However, no research group has yet found a causative gene mutation. Current research shows that

the inheritance and genetics of ET may be much more complex than initially anticipated. The researchers at Duke as well as others have continued to work on ways that they can study the genetics of diseases that show complex inheritance patterns. These include diseases that may be linked to a complex interplay between multiple genes and also the environment. However, the limiting factor in most genetics studies has been the difficulty in recruiting families to participate in these studies. Genetics researchers have stressed how important it is to recruit families, as often the difference in identifying a disease

causing mutation can sometimes come down to just one family or a handful of families. Even those families in which a disease causing mutation is not found are very valuable to future studies. The researchers at Duke continue to recruit families in hopes that the next family may provide the next breakthrough in research.

"Current research shows that the inheritance and genetics of ET may be much more complex than initially anticipated."

For more information on Duke's ET program please visit: http://www.chg.duke.edu/diseases/et.html

About the Author

Hok Morita is currently a third year medical student at the Penn State University College of Medicine. He has had ET since the age of five. He plans to pursue a Neurology residency in hopes of becoming a Movement Disorder Specialist.

On behalf of Tremor Action Network Hok traveled from Pennsylvania to North Carolina to tour the Center for Human Genetics. He received an honorable acknowledgment from Duke University Medical Center for TAN's gift to the CHG for "essential tremor related research." Hok also met with Mark Stacey, MD, Director of the Movement Disorders Program at Duke University.

DRD3 gene

By Hokuto Morita

The past year has seen some exciting findings as well as some disappointments in the study of essential tremor (ET) genetics. As most patients have heard, ET has both sporadic, or non-familial forms, and genetic, or heritable forms. Both genetic studies and epidemiology studies are equally important and advances in one can often lead to advances in the other. Therefore ET researchers who primarily study genetics and those who study environmental factors both agree that gene studies are a very important part of understanding ET.

There is mounting evidence that there is no single "gene" that can explain all the heritable forms of ET. Essential tremor is a disorder that researchers would call "genetically heterogeneous." What this means is that in some families with the heritable form, there might be a mutation in one gene while in another family the ET might be due to a mutation in a different gene. To make

things more complicated, there might be some in which multiple gene mutations are required to express disease. What this means to the researcher is that even if they were to find a mutation that causes ET in a certain set of families, there is still a lot of work to do because there are other families in which ET cannot be explained by that particular mutation.

The approach that researchers take is to find as many families as they can to maximize the probability that they will be able to identify a gene mutation. Even if the mutation were found in only a handful of families it is still significant because it can often shed light into some of the mechanisms of the disease and can often lead to advances in other areas.

To date, no causative gene mutation has been found for ET, although there have been some exciting recent findings in

this area. Some readers may have heard about the genes with funny terms like HS1-BP3 and DRD3, but these have not been shown to contain causative gene mutations. They may confer susceptibility or risk, but the evidence seems to show that these are not causative. This article will provide some information about the recent findings about the gene called DRD3.

The research groups of Gerard Lucotte and Pierre Sokoloff in France have reported some exciting findings in which they have found a change in a gene called DRD3 that seems to be associated with ET in a group of French families with heritable ET. In 24 of 30 French families that they examined, those family members with ET had

this change, or polymorphism, in the DRD3 gene. It is one thing to find a polymorphism, but it's even stronger evidence if you can show that the polymorphism causes some type of change in the function of the gene.

DRD3 stands for Dopamine Receptor Type 3 because that's what the gene produces. Dopamine is a type of

neurotransmitter or substance that some nerve cells use to communicate with each other. The dopamine receptor is at the receiving end of the signal on another nerve cell. So one nerve cell, or neuron, releases dopamine and it binds to a dopamine receptor on another nerve cell, and the signal is passed along.

The researchers postulated that the particular change in the gene DRD3 that they found may change the properties of the dopamine receptor and thus may alter this signaling somehow. In order to study how this particular change in the DNA sequence of the DRD3 affects dopamine signaling, they used cell culture models. They introduced DNA containing the change in DRD3 sequence into cells in a culture dish and observed how it affected the function of the dopamine type 3 receptor. What they found is that the change in sequence caused dopamine to bind more tightly to the dopamine receptor and it also seemed to affect its

"Lucotte and Sokoloff have proposed a very testable hypothesis." signaling function. In other words, the altered DRD3 may cause the signaling between certain nerve cells to be jumbled slightly.

The data seems to show that this change, or polymorphism, in DRD3 is not causative. However, there are some particularly exciting aspects about this study. In the families that were studied there seemed to be a gene dosage effect - in other words, having two bad copies of a gene polymorphism is worse than having one bad copy. For most genes, we have two copies, one from our mother and one from our father. This study showed that in their families, those having two copies with the polymorphism seemed to have younger ages of onset and more severe tremor than those who had only one copy with the polymorphism. For geneticists, demonstrating a gene dosage effect strengthens the evidence that the particular polymorphism or gene mutation has something to do with the disease. In addition, the researchers have shown that the polymorphism in DRD3 alters the functioning of the D3 receptor slightly.

We can't claim this polymorphism is causative however. The researchers' data indicates that in their French population, 46.7% of those with ET had the particular change in DRD3 while 26% of those without ET had that particular change. In a larger sample taken from families at the Baylor College of Medicine, the percentages were even closer. What this means is that even a substantial portion of the normal population, or those without ET, has this particular change in DRD3 but yet they don't develop disease. If the particular gene were causative, we would expect almost all of the patients with the particular mutation to express disease and close to 0% of the normal population without ET having that particular mutation (disregarding something called penetrance). So at best, we can say that the DRD3 polymorphism might be a risk factor or susceptibility factor. In other words, having this particular polymorphism might put you at greater risk for developing ET. However, the effect appears to be small if one exists. The paper claims that the gene is causal, but this has not been actually shown. The search for causative gene mutations continues.....

Even though the researchers probably have not identified a causal gene mutation, the study has many important future implications for ET research. The study by Sokoloff and Lucotte seems to provide strong evidence that there is an association between DRD3 and ET in their French families, and other researchers will want to replicate this finding. Researchers will look at their families and see if there is a difference between the percentages of those containing the DRD3 polymorphisms in ET patients and the normal population without ET.

To date, this finding was not replicable in some other studies- meaning some other researchers could find no significant difference between ET patients and controls. Another way in which the study by Lucotte and Sokoloff may be important is that they have proposed a very testable hypothesis. Their studies may suggest that alterations in dopamine signaling may confer risk to some cases of ET. Researchers will try to examine this hypothesis by trying to replicate the findings and looking at alterations in dopamine pathways using imaging or animal model studies. Clinically, they may try to determine if therapeutics aimed at altering D3 receptors have any affect on cases of ET. Though, the evidence is probably not strong enough to justify creating compounds specifically for this purpose.

Many ET researchers are surprised that no one has yet identified a causative gene mutation in ET. This may be due to multiple factors. Often, the limiting factor is having limited access to families. The more families that participate, the higher the likelihood that a causative gene mutation will be found. Another factor complicating studies is the difficulty in diagnosing and standardizing the diagnosis of ET.

Studies:

Jeanneteau F, Funalot B, Jankovic J, Deng H, Lagarde JP, Lucotte G, Sokoloff P.

A functional variant of the dopamine D3 receptor is associated with risk and age-at-onset of essential tremor.

Proc Natl Acad Sci U S A. 2006 Jul 11;103(28):10753-8. Epub 2006 Jun 29.

PMID: 16809426 [PubMed - indexed for MEDLINE]

Lucotte G, Lagarde JP, Funalot B, Sokoloff P.

Linkage with the Ser9Gly DRD3 polymorphism in essential tremor families.

Clin Genet. 2006 May; 69(5):437-40. No abstract available.

PMID: 16650084 [PubMed - indexed for MEDLINE]

Tan EK, Prakash KM, Fook-Chong S, Yih Y, Chua E, Lum SY, Wong MC, Pavanni R, Zhao Y.

DRD3 variant and risk of essential tremor.

Neurology. 2007 Mar 6;68(10):790-1. No abstract available.

PMID: 17339592 [PubMed - indexed for MEDLINE]

About the Author

Hok Morita is currently a third year medical student at the Penn State University College of Medicine. He has had ET since the age of five. He plans to pursue a Neurology residency in hopes of becoming a Movement Disorder Specialist.

SSDI: The Coming Crisis

By Allsup, Inc.

Social Security Disability Insurance (SSDI) provides regular monthly income to people who can no longer work because of a serious illness or injury. Every working person pays for these benefits through FICA tax deductions.

Problems Mounting in Washington, DC

Today, the Social Security Administration (SSA) and its SSDI program are over-worked, over-loaded and understaffed because of budget cuts and the aging boomer population. Combined with the pending retirements of over 50 percent of SSA employees, the situation will get much worse.

A U.S. House Ways and Means Committee press release recently stated, "Nowhere is the situation more grave than in the processing of applications for disability benefits. Due to large and increasing backlogs, severely disabled individuals can wait years to get the benefits they need

for basic economic survival." The release continued, "At the end of fiscal year 2006, about 1.3 million people were awaiting a decision." In reality, SSA numbers show over 1.4 pending cases at the end of fiscal 2006.

The Ways and Means Subcommittee on Social Security met to discuss the problem on February 14, 2007. At the hearing, Social Security experts warned Congress that the problem will grow even more severe if the status-quo continues.

In written testimony to the subcommittee, Jim Allsup, founder and CEO of Allsup Inc., stated that a public-private partnership might be the solution to the SSDI disability crisis.

He warned of a meltdown in the SSA's disability program, adding that third-party organizations such as his company

"are well-tested and available to assist increasing numbers of individuals with applying for SSDI claims." The former SSA employee added, "Current [disability] claimants are experiencing unacceptable delays in obtaining determinations. Disability applicants and [Social Security Administration] employees need help immediately."

Allsup Inc. is a leading national provider of SSDI representation services.

Delays Across the Country

News articles across the U.S. have brought this crisis to the attention of the public, but those caught in this backlog feel the reality every day.

"Nationwide, the backlog has now reached 1.4 million and continues to grow daily." A recent story in the Columbus Dispatch revealed the waiting lists in just two offices in Ohio to be over 20,000. Nationwide, the backlog has now reached 1.4 million and continues to grow daily.

The delays take place at every level of the application process.

The first level is the initial application. This is where all relevant medical and vocational evidence is submitted to the SSA. Next is the reconsideration level. If a person's initial application is denied, he or she can file an appeal. The backlog at these two levels is about 700,000.

If the reconsideration is denied a person can appeal again. This takes him or her to the hearing level with an administrative law judge hearing. If a person's hearing ends in a denial, he or she may submit an appeal to the Appeals Council. The Appeals Council will review the hearing decision to determine if it was rendered properly according to the law. The backlog at these two levels is at approximately 730,000.

If the Appeals Council affirms a denial there is an available appeal to the Federal District Court. There are no

statistics available to track any backlogs at this level.

It is a lengthy process that is made much longer by the building crisis. But securing SSDI benefits means increased monthly income and automatic Medicare benefits. That means awardees will receive medical benefits, prescription drug coverage, protected retirement benefits, benefits for dependents and return-to-work incentives.

About the Author

Allsup is always available to help the applicant through the process. Allsup has helped tens of thousands of people get the benefits they deserve. Founded in 1984, Allsup Inc. is the nation's premier provider of Social Security Disability benefits. For more information on how Allsup can help you file for SSDI, visit http://www.allsup.com/TAN/.



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