Meet Desmoid Tumor Warrior DEANN

In 1996, my oncologist had no idea what he was dealing with because he had no information about desmoids. He recommended amputation, but I wanted to save my leg. I underwent 6 surgeries to remove the mass and repair the damage it had caused. The left me with 40% blood circulation and nerve damage, and I am permanently paralyzed from the knees down. Ten years after my original diagnosis, I found a second tumor in my right shoulder. Surgery didn’t help. I was told to accept the pain and continue on the medication. I refused, and continued my treatment, along with radiation, radiation and我都继续做我的治疗，但最终没有效果。我选择了一种自然疗法，叫做Desmoid, and I continue to get older and my remission tincture. my tumors are slowly shrinking. I am still permanently disfigured and paralyzed, but after 22 years, my tumors are finally under control.

I was a 25-year-old loan officer and mother of 3 small kids when I was diagnosed. I have been unable to work a conventional job since then. Now I'm an admin of a patient support group page called the Desmoidian. I know there wasn't much research being done at the time, but I am so thankful it is being done now. There are more treatment options given to patients today, and I expect that with continuing research the treatment options will be better and more catered to this disease. I have watched the science change patient outcomes and it is amazing to see.

In 1996, my oncologist had no idea what he was dealing with because he had no information about desmoids. He recommended amputation, but I wanted to save my leg. I underwent 6 surgeries to remove the mass and repair the damage it had caused. This left me with 40% blood circulation and nerve damage, and I am permanently paralyzed from the knees down. Ten years after my original diagnosis, I found a second tumor in my right shoulder. Surgery didn’t help. I was told to accept the pain and continue on the medication. I refused, and continued my treatment, along with radiation, radiation and我都继续做我的治疗，但最终没有效果。我选择了一种自然疗法，叫做Desmoid, and I continue to get older and my remission tincture. my tumors are slowly shrinking. I am still permanently disfigured and paralyzed, but after 22 years, my tumors are finally under control.

I was a 25-year-old loan officer and mother of 3 small kids when I was diagnosed. I have been unable to work a conventional job since then. Now I'm an admin of a patient support group page called the Desmoidian. I know there wasn't much research being done at the time, but I am so thankful it is being done now. There are more treatment options given to patients today, and I expect that with continuing research the treatment options will be better and more catered to this disease. I have watched the science change patient outcomes and it is amazing to see.

In 1996, my oncologist had no idea what he was dealing with because he had no information about desmoids. He recommended amputation, but I wanted to save my leg. I underwent 6 surgeries to remove the mass and repair the damage it had caused. This left me with 40% blood circulation and nerve damage, and I am permanently paralyzed from the knees down. Ten years after my original diagnosis, I found a second tumor in my right shoulder. Surgery didn’t help. I was told to accept the pain and continue on the medication. I refused, and continued my treatment, along with radiation, radiation and我都继续做我的治疗，但最终没有效果。我选择了一种自然疗法，叫做Desmoid, and I continue to get older and my remission tincture. my tumors are slowly shrinking. I am still permanently disfigured and paralyzed, but after 22 years, my tumors are finally under control.

I was a 25-year-old loan officer and mother of 3 small kids when I was diagnosed. I have been unable to work a conventional job since then. Now I'm an admin of a patient support group page called the Desmoidian. I know there wasn't much research being done at the time, but I am so thankful it is being done now. There are more treatment options given to patients today, and I expect that with continuing research the treatment options will be better and more catered to this disease. I have watched the science change patient outcomes and it is amazing to see.

In 1996, my oncologist had no idea what he was dealing with because he had no information about desmoids. He recommended amputation, but I wanted to save my leg. I underwent 6 surgeries to remove the mass and repair the damage it had caused. This left me with 40% blood circulation and nerve damage, and I am permanently paralyzed from the knees down. Ten years after my original diagnosis, I found a second tumor in my right shoulder. Surgery didn’t help. I was told to accept the pain and continue on the medication. I refused, and continued my treatment, along with radiation, radiation and我都继续做我的治疗，但最终没有效果。我选择了一种自然疗法，叫做Desmoid, and I continue to get older and my remission tincture. my tumors are slowly shrinking. I am still permanently disfigured and paralyzed, but after 22 years, my tumors are finally under control.

I was a 25-year-old loan officer and mother of 3 small kids when I was diagnosed. I have been unable to work a conventional job since then. Now I'm an admin of a patient support group page called the Desmoidian. I know there wasn't much research being done at the time, but I am so thankful it is being done now. There are more treatment options given to patients today, and I expect that with continuing research the treatment options will be better and more catered to this disease. I have watched the science change patient outcomes and it is amazing to see.

In 1996, my oncologist had no idea what he was dealing with because he had no information about desmoids. He recommended amputation, but I wanted to save my leg. I underwent 6 surgeries to remove the mass and repair the damage it had caused. This left me with 40% blood circulation and nerve damage, and I am permanently paralyzed from the knees down. Ten years after my original diagnosis, I found a second tumor in my right shoulder. Surgery didn’t help. I was told to accept the pain and continue on the medication. I refused, and continued my treatment, along with radiation, radiation and我都继续做我的治疗，但最终没有效果。我选择了一种自然疗法，叫做Desmoid, and I continue to get older and my remission tincture. my tumors are slowly shrinking. I am still permanently disfigured and paralyzed, but after 22 years, my tumors are finally under control.

I was a 25-year-old loan officer and mother of 3 small kids when I was diagnosed. I have been unable to work a conventional job since then. Now I'm an admin of a patient support group page called the Desmoidian. I know there wasn't much research being done at the time, but I am so thankful it is being done now. There are more treatment options given to patients today, and I expect that with continuing research the treatment options will be better and more catered to this disease. I have watched the science change patient outcomes and it is amazing to see.

Introduction

Desmoid tumor is also called aggressive fibromatosis, as it has similarities with a malignant (cancerous) tumor called fibrosarcoma. It is, however, considered benign because it does not metastasize (spread) to other parts of the body.

Signs and Symptoms

While each child or adult may experience symptoms differently, the following are the most common symptoms of desmoid tumors. The symptoms vary greatly depending on size and location:

• A painless swelling or lump
• Pain or soreness caused by compressed nerves or muscles
• Pain and obstruction of the bowels
• Limping or other difficulty with using the legs, feet, arms, and/or hands or other affected parts of the body

Causes

The cause of desmoid tumor remains unknown. Desmoid tumors may present sporadically or as a manifestation of hereditary familial adenomatous polyposis (FAP). FAP is a familial cancer predisposition syndrome which, if left untreated, results in colorectal cancer. Up to 32% of patients with FAP will develop desmoid tumors in their lifetime. These desmoid tumors are the result of mutations, or changes, in the adenomatous polyposis coli APC gene.
Charlotte (written by her mom, Rebecca)

My daughter Charlotte and I migrated from the UK to Australia when Charlotte was 7 years old. Here we created a lovely life—going to work and school, being an arm’s length away from our children and Deeply our family, and Mother’s Day. In 2014, I found my best friend John and we became a blended family with 6 children between us, ranging from 1 year old to 20. I am a lawyer and my husband is in law enforcement.

Our journey has been one of discovery. We found some of the most talented and caring health professionals, a Facebook group filled with people who have been there. We love our family, friends, and home of community. As a mother, I experienced a huge, sense of responsibility to ensure that I was thoroughly educated so that I could make the best decisions for Charlotte.

In 2016, Charlotte graduated high school, attended her prom, and was looking forward to a bright future when she was diagnosed with a desmoid extra-abdominal tumor. Charlotte’s extra-abdominal desmoid tumor had been incorrectly noted on admission as a dermoid cyst. Charlotte has been treated with surgery and chemotherapy.

Meet Desmoid Tumor Warrior CHARLOTTE

What is DESMOID TUMOR?

continued from page 75

In most patients, desmoid tumor occurs sporadically, meaning that it is not caused by predisposing genetic disease. People who develop desmoid tumors sporadically have no other APC gene–associated health problems. Repeated in patient or trauma to a certain body area, including surgical trauma, may increase the risk of developing desmoid tumor, and estrogen may also show a role in its development.

Affected Populations

Desmoid tumors constitute 0.03% of all tumors. The estimated incidence in the general population is 5 to 6 per million people per year. Desmoid tumors are observed to be more common in persons aged 20 to 40 years, but they may occur in other age groups, too. Desmoid tumors, which may commonly first occur in women after childbirth, have a female-to-male gender ratio of 2:1. The gender incidence is the same in children.

Related Disorders

Gardner's syndrome is a genetic disorder characterized by multiple colonic polyps and tumors outside the colon. The extra-abdominal tumors may include osteomas of the skull, thyroid cancer, epidermoid cysts, fibromas, and sebaceous cysts, and the multiple polyps predispose an individual to the development of colon cancer. Gardner's syndrome, caused by a mutation in the APC gene located on chromosome 5q21, is recognized as a phenotypic variant of FAP. Typically, as one parent has Gardner's syndrome, each of his or her male or female children are at 50% risk of inheriting the APC gene and manifesting Gardner's syndrome themselves.

Dermatofibrosarcoma is a cutaneous malignancy that arises from the dermis and invades deeper subcutaneous tissue such as fat tissue, fascia, muscle, and also bone. Its cause is unknown. Chromosomal aberrations may contribute to the pathogenesis of dermatofibrosarcoma, especially a chromosomal translocation (t7;22) that fuses the collagen gene (COL1A1) with the platelet-deprived growth factor gene. No evidence of hereditary or familial predisposition exists, and in 10% to 20% of affected patients, trauma at the site may be incriminated. Surgical excision, with deep and wide excision of margins and also bone resection, is the recommended treatment. Despite surgery and radiation therapy, distant metastasis may occur.

Dermatofibrosarcoma prototypic, or atypical, is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a relatively slow-growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque. Dermatofibrosarcoma is a slowly growing tumor. Because of slow progression and initial growth as a small asymptomatic nodule or evolve into an atrophic and/or sclerotic plaque.
Meet Desmoid Tumor Warrior ANNA

In 2017, I had a golf ball-sized lump right above my navel that started to hurt. I ended up in the ER because we thought it might be a hernia. Tests ruled that out, and I was sent to a general surgeon who told me I had the choice of leaving it alone or removing the tumor. I went with removal of the lump because that is what I had wanted to do, but the surgeon said it was not an option for her to remove it and referred me to UCHealth to be seen by a sarcoma specialist. Dr. V and I went on to do four surgeries, and I had another scan six months after each surgery. I continued to think surgery would resolve the issue, but it did not. In fact, by the fourth surgery, the tumor was getting bigger! Dr. V thought the tumor was an abdominal wall desmoid tumor. We did another scan, and the tumor continued to grow. It was then that I was referred to a sarcoma specialist at the University of Colorado. An MRI and biopsy were done, and I was told it was a recurrence of my abdominal wall desmoid tumor. Because it was growing, it was not recommended, and after discussing all the options, I went with chemo of vinblastine and methotrexate and a watch-and-wait policy. After treatment #14, my tumor was small enough to begin a watch-and-wait regimen after treatment #14. I had another scan 6 months later and it was down to the size of a raisin! Because of the side effects, Dr. V thought the tumor may cause significant morbidity and even mortality, patients with asymptomatic or minimally symptomatic disease with stable appearance on screening, may appropriately be treated with a period of watchful waiting.

I am 54 years old, and my husband and I live out in the country in southern Colorado. My husband works at UCHealth, and my tumor was GONE!

I had another scan 6 months later, and my tumor was gone! It was the outpouring of love and support of family and friends that got me through this ordeal. My mantra was “A positive attitude leads to positive outcomes.” NEVER GIVE UP! A dear friend of mine who is a doctor of clinical psychology has a quote which I find so true: “A positive attitude leads to positive outcomes.”

It was the outpouring of love and support of family and friends that got me through this ordeal. My mantra was "A positive attitude leads to positive outcomes. NEVER GIVE UP! A dear friend has a quote which I find so true: "A positive attitude leads to positive outcomes." I had another scan 6 months later, and my tumor was GONE!

I love my life. I love my husband and I live out in the country in southern Colorado. My husband works at the local animal hospital and I work part time as a nurse as a virtual assistant and the remainder of the time as a happy homemaker.

Standard Therapies

TREATMENT

Depending on the extent of tumor growth and the overall condition of the patient, the following treatment options are utilized. Surgery alone is often the only treatment needed; however, the recurrence rate of desmoid tumor is often as high as 30%, and more than one surgery may be required. The tumor tends to become more aggressive with repeated surgeries. Surgery alone is often the only treatment needed, however, the recurrence rate of desmoid tumor is often as high as 30%, and more than one surgery may be needed. The tumor tends to become more aggressive with repeated surgeries.

Chemotherapy:

Drugs such as mitomycin (generic Gleevec®) are used to treat desmoid tumors.

Hormone therapy:

Some hormones seem to promote the growth of desmoid tumors, so anti-hormonal medications such as anti-estrogens and prostaglandin inhibitors may also be used therapeutically.

Diagnosis

The conclusive diagnosis of desmoid tumors requires a biopsy. The spindle cells of desmoid tumors appear to be myofibroblasts. The spindle cells are thought to be an abnormal proliferation of myofibroblasts, which normally disappear gradually during the later stages of wound healing. Additionally, immunohistochemical stains can establish the nuclear accumulation of beta-catenin, a protein caused by the genetic mutations usually found in desmoid tumors. Nuclear reactivity shows relatively high specificity, detected in up to 90% of desmoids, regardless of site. Finally, antibodies are often examined in desmoid tumors, including smooth muscle actin, desmin, and KIT, to aid in distinguishing them from other tumors.

What is DESMOID TUMOR?

children less than one year of age. It presents as a rapidly growing mass at birth or shortly after. This fibrosarcoma is usually slow growing, and tends to be more benign than fibrosarcoma in older children, which behaves more like the type found in adults. Adult-form fibrosarcoma may occur in older children and in adolescents, especially those between the ages of 10 to 15.

Continued from page 77.

Continued from page 77.

Continued from page 77.

These may cause the tumor to slowly shrink. Non-steroidal anti-inflammatory drugs (NSAIDs) and anti-inflammatory agents such as imatinib (generic Gleevec®) may also be used therapeutically.

Surgery:

If surgeons cannot remove the desmoid tumor because of size or location, chemotherapy may be used to reduce tumor size. Agents include doxorubicin (Adriamycin®, Rubex®), dacarbazine (DTIC-Dome®), and carboplatin (Paraplatin®).
Kinases are regulators of cell growth, differentiation, and motility. Because these processes are deregulated in tumors cells, a new class of drugs called receptor kinase inhibitors has been developed. Gleevec and sorafenib (Nexavar®) are two kinase inhibitors useful in treating desmoid tumors.

Radiation therapy: As a treatment for recurrent disease or as a primary therapy to avoid mutilating surgical resection, radiation is high-energy rays from a specialized machine to damage or kill cancer cells and to shrink tumors.

Monitoring: After surgery, magnetic resonance imaging (MRI) is used to monitor recurrence in the arms and legs. Computed tomography (CT) scans are used to monitor intra-abdominal and chest desmoids.

Investigational Therapies

Angiogenesis inhibitors: Newer substances that may be able to prevent the growth of tumors by blocking formation of new blood vessels that feed the tumors are being currently investigated.

Chemotherapy agents: Researchers are also testing several chemotherapy drugs, or combinations of drugs, that could prove to be more effective in treating desmoid tumors to avoid radical management via surgery.

Mutations in the gene for beta-catenin have been found to commonly occur in desmoid tumors. Mutation analysis may soon prove to be most effective in treating desmoid tumors to avoid radical management via surgery.

Information on current clinical trials is posted on the Internet at www.clinicaltrials.gov. All studies receiving US government funding, and some supported by private industry, are posted on this government web site.

For information about clinical trials being conducted at the NIH Clinical Center in Bethesda, MD, contact the National Institutes of Health (NIH) Patient Recruitment Office:

Email: prpl@cc.nih.gov
TTY: (866) 411-1222
Toll-Free: (800) 411-1010

For information about clinical trials sponsored by private sources, contact:

www.rarediseases.org

Email: info@oncologywatch.com
TTY: (866) 411-1010
Toll-Free: (800) 411-1222

For information about clinical trials being conducted in Europe, contact:

www.clinicaltrialsregister.eu

What is DESMOID TUMOR?

continued from page 79

Investigational Therapies

Angiogenesis inhibitors: Newer substances that may be able to prevent the growth of tumors by blocking formation of new blood vessels that feed the tumors are being currently investigated.

Chemotherapy agents: Researchers are also testing several chemotherapy drugs, or combinations of drugs, that could prove to be more effective in treating desmoid tumors to avoid radical management via surgery.

Mutations in the gene for beta-catenin have been found to commonly occur in desmoid tumors. Mutation analysis may soon be used to predict the risk of recurrence and to aid in the design of individual therapies.

Information on current clinical trials is posted on the Internet at www.clinicaltrials.gov. All studies receiving US government funding, and some supported by private industry, are posted on this government web site.

For information about clinical trials being conducted at the NIH Clinical Center in Bethesda, MD, contact the National Institutes of Health (NIH) Patient Recruitment Office:

Email: prpl@cc.nih.gov
TTY: (866) 411-1010
Toll-Free: (800) 411-1222

For information about clinical trials sponsored by private sources, contact:

www.rarediseases.org

Email: info@oncologywatch.com
TTY: (866) 411-1010
Toll-Free: (800) 411-1222

For information about clinical trials being conducted in Europe, contact:

www.clinicaltrialsregister.eu

Meet Desmoid Tumor Warrior TIFFANY

My name is Tiffany. I am 35, married with two beautiful children, and work full time as a medical biller for a local pediatric office. I was 26 and pregnant with our second child when something ‘felt off’—I asked my midwife about an odd feeling in my left hip. I didn’t think it was right, but it did hurt. Right, the midwife thought, so I went to a specialist, which diagnostically, was my hip or sciatic nerve. I was made complete more sense. About a month after our son was born, my 2-year-old daughter stumbled down the couch where I was lying. I was absolutely in shock at the sight of her blood. I felt the same way had it been my pelvis. I asked my PCP, Dr. Hay, MRI, and lab work all showed normal results. It was then painful, and I felt it to be a pain. My left hip seemed to grow larger than the right, but everyone said it felt normal.

I went to every doctor I could visit for the next 5 years. They all said the same. No one knew what was making me feel so weak and tired. I was told to see a specialist, but I was afraid of the pain and I was having trouble walking. I tried every day. Other than outcome evaluations didn’t provide any reassurance so I decided to stick at night for pain relief and deep. My PCP suggested I see a pain management provider for further pain management. I thought it was nothing, but I was sent to the end. After a few appointments, she seemed to have picked up some food, so I had an MRI. I had a strange case of sciatica that had been growing and spreading into my right arm over 2 years. I was sent to a specialist in Pittsburgh, who explained that I had a desmoid tumor.

He said he could remove it if I wanted, but because the recurrence rate is high, the patient is not fast to remove these unless necessary. The pain was debilitating, so I took it. I removed. The tumor grew back within a year longer than the first one, but this time only because my tumor developed outside of my vagina, so removal and treatment were not only that easy. Because I had a recurrence, however, I wanted radiation. It was a little over a year since my second surgery and the tumor is stable. A lot of much less mass has been removed from my left arm, so I both with deep and I was regularly undecidable, though not usually in pain.

The radiation treatment, which hopefully halted tumor growth permanently, has also essentially ended all other visceral organs that will prevent pain and organ evaporation. The biggest hurdle was the fear that I would have trouble getting pregnant or making it with labor. After the MRI that confirmed a tumor, a CT scan was done and read as normal. In any case, I was not sure that there are any one solution, but I am most disappointed that the infusion that I was given was so lacking knowledge. Looking back, not one more way the way I thought I would be at that time. Because I didn’t know what to do, I had to be taken to a different level of care, but perhaps I had no more options in that way. I could’ve been diagnosed earlier.
Meet Desmoid Tumor Warrior

MATT

I am a 46-year-old father, loving husband, and bowler, and eaglehawk, or at least now just a patient with a desmoid tumor. I first noticed a growth on my abdomen in December of 2015. The growth was not painful, just a firm mass that was visible through my skin. I was immediately referred to a surgeon in Rochester, New York who sent me to Cleveland Clinic for further evaluation. My surgeon removed the growth in May of 2016 and it was confirmed to be a desmoid tumor. I was referred to my local community hospital for follow-up care, and the surgeon had the growth analyzed and genetically tested. The test showed I carry a mutation in the ALK gene.

In March of 2017, I noticed a second growth on my right breast that was causing pain and discomfort. I was referred to an oncologist at the University of Rochester to have the growth removed. It was discovered that the tumor had grown very rapidly and had spread to my bones, liver, and lungs. I was referred to Dr. Chen at the Mayo Clinic in Rochester, Minnesota to seek help. After 8 months, I went to Northwestern Hospital in Chicago, Illinois, for treatment. I was put on Proton Therapy and my tumor continued to shrink. I was discharged in January of 2018 and was able to return to work in February. I am grateful for the medical care I have received and am hopeful that I will be able to continue to live my life as normally as possible.

I am a 36-year-old father, loving husband, avid bowler, and workaholic, or at least I was until my journey with desmoid tumor began. In my early 20s I was diagnosed with familial adenomatous polyposis syndrome, which (I) figured I would never have, as my family history is negative and I never even passed family history down to my children. In December of 2015, I noticed a growth on my abdomen in December of 2015. The growth was not painful, just a firm mass that was visible through my skin. I was immediately referred to a surgeon in Rochester, New York who sent me to Cleveland Clinic for further evaluation. My surgeon removed the growth in May of 2016 and it was confirmed to be a desmoid tumor. I was referred to my local community hospital for follow-up care, and the surgeon had the growth analyzed and genetically tested. The test showed I carry a mutation in the ALK gene.

In March of 2017, I noticed a second growth on my right breast that was causing pain and discomfort. I was referred to an oncologist at the University of Rochester to have the growth removed. It was discovered that the tumor had grown very rapidly and had spread to my bones, liver, and lungs. I was referred to Dr. Chen at the Mayo Clinic in Rochester, Minnesota to seek help. After 8 months, I went to Northwestern Hospital in Chicago, Illinois, for treatment. I was put on Proton Therapy and my tumor continued to shrink. I was discharged in January of 2018 and was able to return to work in February. I am grateful for the medical care I have received and am hopeful that I will be able to continue to live my life as normally as possible.

I am a 36-year-old father, loving husband, avid bowler, and workaholic, or at least I was until my journey with desmoid tumor began. In my early 20s I was diagnosed with familial adenomatous polyposis syndrome, which (I) figured I would never have, as my family history is negative and I never even passed family history down to my children. In December of 2015, I noticed a growth on my abdomen in December of 2015. The growth was not painful, just a firm mass that was visible through my skin. I was immediately referred to a surgeon in Rochester, New York who sent me to Cleveland Clinic for further evaluation. My surgeon removed the growth in May of 2016 and it was confirmed to be a desmoid tumor. I was referred to my local community hospital for follow-up care, and the surgeon had the growth analyzed and genetically tested. The test showed I carry a mutation in the ALK gene.

In March of 2017, I noticed a second growth on my right breast that was causing pain and discomfort. I was referred to an oncologist at the University of Rochester to have the growth removed. It was discovered that the tumor had grown very rapidly and had spread to my bones, liver, and lungs. I was referred to Dr. Chen at the Mayo Clinic in Rochester, Minnesota to seek help. After 8 months, I went to Northwestern Hospital in Chicago, Illinois, for treatment. I was put on Proton Therapy and my tumor continued to shrink. I was discharged in January of 2018 and was able to return to work in February. I am grateful for the medical care I have received and am hopeful that I will be able to continue to live my life as normally as possible.

I am a 36-year-old father, loving husband, avid bowler, and workaholic, or at least I was until my journey with desmoid tumor began. In my early 20s I was diagnosed with familial adenomatous polyposis syndrome, which (I) figured I would never have, as my family history is negative and I never even passed family history down to my children. In December of 2015, I noticed a growth on my abdomen in December of 2015. The growth was not painful, just a firm mass that was visible through my skin. I was immediately referred to a surgeon in Rochester, New York who sent me to Cleveland Clinic for further evaluation. My surgeon removed the growth in May of 2016 and it was confirmed to be a desmoid tumor. I was referred to my local community hospital for follow-up care, and the surgeon had the growth analyzed and genetically tested. The test showed I carry a mutation in the ALK gene.

In March of 2017, I noticed a second growth on my right breast that was causing pain and discomfort. I was referred to an oncologist at the University of Rochester to have the growth removed. It was discovered that the tumor had grown very rapidly and had spread to my bones, liver, and lungs. I was referred to Dr. Chen at the Mayo Clinic in Rochester, Minnesota to seek help. After 8 months, I went to Northwestern Hospital in Chicago, Illinois, for treatment. I was put on Proton Therapy and my tumor continued to shrink. I was discharged in January of 2018 and was able to return to work in February. I am grateful for the medical care I have received and am hopeful that I will be able to continue to live my life as normally as possible.

Who we are: THE DESMOID TUMOR RESEARCH FOUNDATION

The mission of the Desmoid Tumor Research Foundation (DTRF) is to aggressively fund research to accelerate the development of improved therapies, and ultimately find a cure for desmoid tumors. The DTRF also collaborates with dedicated researchers and clinicians worldwide to improve the lives of patients through education, awareness, and support.

Research funding: Founded in 2005, the DTRF is the only foundation in the United States solely dedicated to funding desmoid tumor research and to finding a cure for this rare disease. The funding of cutting-edge collaborative research at the world’s top sarcoma research centers is the DTRF’s priority. Researchers are making significant advancements as new clinical trials and treatments emerge. Discoveries made through desmoid tumor research may also potentially be applied to many other more common diseases such as colon, breast, and ovarian cancers. The DTRF’s Scientific and Medical Advisory Boards comprise the world’s top desmoid tumor experts.

Patient support: The DTRF holds an annual fall Patient Meeting and regional patient meetings that bring patients, physicians, and researchers together for education, support, and collaboration. These meetings provide a supportive environment for patient interaction and informative lectures by clinicians and researchers. Most of all, we support patients by being a supportive partner in fighting this disease and inspiring hope through funding research for a cure.

Research workshops and international collaboration: The annual DTRF International Desmoid Tumor Research Workshop brings together a diverse group of scientists from around the world, including experts in desmoid tumor research, human genetics, drug development, and related fields. The Workshop facilitates an enthusiastic and collegial atmosphere as researchers across disciplines and institutions collaborate around the shared goal of improving treatments for patients with desmoid tumor, establishing research priorities, and moving the field forward toward a cure. The DTRF also helped fund the first International Consensus Paper of experts from around the world on the medical treatment of desmoid tumors.

Patient registry: The DTRF partners with NORD and the FDA to maintain the first-ever patient registry in the United States specifically for patients with desmoid tumor. This registry collects and aggregates data from patients and makes the de-identified data available to researchers to advance the medical science of desmoid tumors.

Virtual tumor board: The DTRF maintains the international DTRF Virtual Tumor Board which provides access to experts in desmoid tumor research, including clinicians, radiologists, pathologists, and other experts from around the world, monthly via videoconference. The resource offers a new source of support and collaboration for physicians to present their difficult cases of desmoid tumor.

Website: The DTRF’s website, www.dtrf.org, is a clearhouse of information on desmoid tumors and published desmoid tumor research. Its target reach comprises physicians, researchers, and patients around the globe. The organization provides patients with critical information and also directs them to additional resources for support.

For more information or to donate to help support desmoid tumor research, please visit www.dtrf.org.
My name is Christina, and I have a desmoid tumor. I’m a teacher at an all-girls school in New Jersey, where I teach drama and theology. In addition to teaching, I direct and choreograph many of the school’s productions and also perform in local community theater productions.

My diagnosis process began in January 2017 when I noticed a decreased range of motion in my right shoulder, which became sore and slightly painful. As a yoga teacher and practitioner, I challenged my range of motion and strength daily by playing with arm balances and handstands. My chest began to look swollen, and after seeking imaging, I was told I had a lipoma. I was seen by a general surgeon and underwent surgery on September 29, 2017 to remove the suspected lipoma. When I came out of surgery, I was heartbroken to learn that the doctor described the surgery as “confusing.” During the procedure, no lipoma was located. By October, my symptoms worsened, and after seeking additional help at the University of Pennsylvania, I was finally told that I had a desmoid tumor. I was recommended to see a specialist and start treatment.

I was asked to participate in a clinical trial to test a new medication for desmoid tumors. I was hopeful that this new treatment would eventually shrink my tumor. We need to change the perception of desmoid tumors within the medical community in particular and in the world at large. While some doctors do not consider desmoid tumors cancer, very few understand that they can be as deadly as their cancerous counterparts. Desmoid tumors are erratic, unpredictable, and extremely recurrent in nature. Doctors need to take patients at their word when they say their lives are harder and irrevocably more challenging because of this diagnosis. For me, documenting my journey on a blog has allowed me to express myself and share my story to help others who may be facing a similar situation.

Doctors need to take patients at their word when they say their lives are harder and irrevocably more challenging because of this diagnosis. For me, documenting my journey on a blog has allowed me to express myself and share my story, which has eventually led me to a better quality of life.

Desmoid tumors develop in connective tissues of the body. While these tumors do not have the capacity to spread distantly (metastasize) through the body, they are able to invade surrounding tissues. When that occurs, it results in destruction of vital structures, compromised organ function, debilitating pain, and other serious and sometimes fatal complications. The diagnosis rate of 5 to 6 per 1 million people annually may be an underestimate of the actual affected population due to differences in correctly diagnosing the disease. To improve awareness of desmoid tumors and to better inform treatment development, the DTRF, in partnership with NORD, launched the DTRF Desmoid Tumor Patient Registry and Natural History Study (NHS).

Here, we describe patient demographics, tumor location, and quality of life in the NHS patient population.

As of January 2019, 357 patients have completed 2,371 surveys.

The NHS participants are mostly white (88%, 313/357) and female (78%, 277/357). Ongoing recruitment efforts are poised to address the sampling bias apparent to date with increased outreach to sarcoma centers around the world. Patients reside in 27 countries; 80% (285/357) are US-based. Median age at diagnosis is 33 years (mean of 32.6 years). The time from onset of symptoms to diagnosis was more than 1 year for 53% (198/357). Moreover, the time to diagnosis was more than 10 years for 8% (29/357) of respondents.

Quality of life was reported as excellent for 27% (94/357) of patients without current tumors, while only 13% (46/357) of those with current tumors reported excellent quality of life, which is statistically significant (p=0.020). Desmoid tumor location was reported for 119 respondents at time of data collection. The most prevalent tumor locations were joint/extremities (33%, 12/357), chest wall (28%, 10/357), and abdominal wall (24%, 10/357). Multiple tumor locations were indicated for 22% (22/119) of patients. Quality of life varied based upon tumor location; it was reported as very good or excellent from 28% (27/97) of patients currently with tumors located in the head and neck to 60% (65/108) of patients with tumors located in the abdominal wall, though the difference was not statistically significant, possibly due to small sample size (p=0.142).

Though the sample size for specific locations of tumors is small, data collection through the registry is ongoing.
Meet Desmoid Tumor Warrior SHONEY

My name is Shoney. My 4-year-old daughter was born by C-section. My postpartum recovery was uneventful. I returned to work after 2 weeks and probably could have used another week due to how physically demanding my job is.

I ended up going back to work after 2 weeks and probably could have used another week due to how physically demanding my job is.

At this point I became obsessed with trying to figure out what this mass was. By the time I received the results from the biopsy I already knew it was a desmoid tumor.

I was then told to make an appointment at the Breast Clinic and underwent an MRI. I was scheduled with a sonographer. I'm a single mom with a 4-year-old daughter and a two-and-a-half-year old son.

The morning of my surgery, I put on my shirt that I had made with Baby Groot. I was extremely anxious, but the surgeon and oncologist a few days before surgery, and they assured me surgery and possibly radiation were the best options.

My biggest struggle was trying to get clear and concise answers with how to proceed. I kept hearing a lot of mumbo jumbo and not much information was being shared. The sono was normal. In July I decided to have the Mirena removed.

Coincidentally, in Oct 2017 I decided to get the Mirena IUD. But in 2018, I started to notice that I was having many problems with the IUD, more research with birth control and its affects needs to be included. It was a very big coincidence that I found the lump after getting the IUD and not after having my children. I asked to have the sono to look for estrogen receptors and it came back negative, and no one seems to be sure. Also, a woman stated if you need to be on your, as those provided by the National Comprehensive Cancer Network (NCCN) Guidelines. They provide these data to understand these new tables to guide both providers and patients.

Most patients in the registry were diagnosed in less than one year after the onset of symptoms, however, for 8% of participants, diagnosis was made more than 10 years after the onset of symptoms.

The number of participants who rated their quality of life as excellent varied significantly depending on whether or not the participant had a desmoid tumors.
Dr. Raphael Pollock

Meet Desmoid Tumor Warrior

How many patients with desmoid tumors do you see in a year?
Approximately 25 newly diagnosed patients per year.

How many FAP cases vs sporadic?
95% are sporadic.

How many patients with desmoid tumors do you see in a year?
An estimated 25 newly diagnosed patients per year.

How did I get to where I am?
My interest in desmoid tumors extends back 35 years to when I was in training as a Fellow in Surgical Oncology at the University of Texas MD Anderson Cancer Center. The challenge of working with this group of patients by helping to improve surgery, radiation, and various systemic therapies has been a driving force in my career. I have worked to bridge the gap between research and clinical care, and to advance care for these patients.

Who am I?
I am a soft tissue tumor surgical oncologist as well as translational researcher in these diseases. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

How can I be of service to you?
I am always happy to do a teleconference!

Is there a mechanism for consulting with patients who can’t travel to see you in person?
Yes, I am always happy to do a teleconference!

Who am I?
I am a soft tissue tumor surgical oncologist as well as translational researcher in these diseases. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

Meet Desmoid Tumor Warrior

Dr. Aaron Weiss

I am a pediatric hematology-oncologist atNationwide Children’s Hospital in Columbus, Ohio, where I lead a large research group focused on desmoid tumors. I am passionate about improving outcomes for children with desmoid tumors and am dedicated to finding new treatments to improve their lives.

How many are FAP cases vs sporadic?
Approximately 25 newly diagnosed patients per year.

Approximately 25 newly diagnosed patients per year.

Approximately 25 newly diagnosed patients per year.

Approximately 25 newly diagnosed patients per year.

Approximately 25 newly diagnosed patients per year.

How many patients with desmoid tumors do you see in a year?
An estimated 25 newly diagnosed patients per year.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

How many patients with desmoid tumors do you see in a year?
An estimated 25 newly diagnosed patients per year.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.

How many patients with desmoid tumors do you see in a year?
An estimated 25 newly diagnosed patients per year.

What is my biggest challenge?
The challenge of understanding the molecular drivers of this disease, and in the development of new therapies for this challenging and often devastating condition. I have been actively involved in the management of desmoid tumors, both of the familial and sporadic types, for more than 35 years. I was at the University of Texas MD Anderson Cancer Center for 31 years, the last 17 of which I served as Head of the Division of Surgery. I was recruited to The Ohio State University Wexner Medical Center in 2013 to serve as Director of the Division of Surgical Oncology. My particular interest is in the molecular and genetic drivers of this disease, and in the development of new therapies for this challenging and often devastating condition.

What would help?
Improved funding for rare diseases such as desmoid tumors is desperately needed. The rarity of the disease, however, means it is difficult to attract funding prioritization.