

## Chordoma: The 1 In A Million Cancer

Chordomas are rare tumors that occur in one out of one million people. They are malignant tumors that tend to grow slowly and can spread to other parts of the body.

They can often be confused with other diseases. And because of their unique self-seeding nature, proper treatment decreases the chances that they'll spread and reoccur. Therefore, it's extremely important to find a care team that is experienced in diagnosing, treating and following patients with chordomas.

Internationally renowned chordoma surgeon Jean-Paul Wolinsky, MD, and chordoma radiation oncologist Vinai Gondi, MD, are experienced specialists recognized by the Chordoma Foundation for their expertise. Dr. Wolinsky, who sees patients at Northwestern Medicine Chordoma Center, is one of the few physicians in the world who has experience performing the complex procedure to remove spinal chordomas. Dr. Gondi specializes in proton therapy and radiosurgery, and performs both treatments on chordomas at Northwestern Medicine's Chicago Proton Center, the only proton center in Illinois.

Here they discuss the treatment of chordomas and how Northwestern Medicine is on the quest for better outcomes.

### Like a Dandelion: A Self-Seeding Tumor

Not only are chordomas rare, treatment includes highly complex procedures that require extensive training.

Consider a dandelion: When you blow the seeds, they self-plant and begin to grow where they land. Likewise, a chordoma is one of the few tumors that can "seed" its cells to surrounding tissues. If a tumor is ruptured in surgery, tumor cells will spill into surrounding areas, planting new seeds that will grow into new tumors.

"When we remove the tumor, we have to ensure there is no spillage of cells," says Dr. Wolinsky, who has performed more than 100 chordoma surgeries. The procedure takes a team of specialists from a variety of fields, from anesthesiology to plastic surgery. Together, they work for 10 to 14 hours to completely remove the tumor, intact, without spillage. Depending on the location of the tumor, bone may need to be removed as well and replaced with metal grafts, which act as a scaffold for the bone to regenerate itself.

While challenging, Dr. Wolinsky embraces the opportunity to care for patients with chordomas. "It's rewarding because of the impact you can have on lives," he notes. *(Continued on next page)*

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**Dr. Jean-Paul Wolinsky, MD**

#### Understanding Chordomas:

Chordoma tumors develop from cells of a tissue called the notochord and can occur anywhere along the spine, from the base of the skull to the tailbone. Because they tend to be slow-growing tumors, you may not experience symptoms for some time.

## Chordoma: The 1 In A Million Cancer

*The Sharper Edge of Proton Therapy*

Chordoma treatment also typically requires highly complex radiation therapy in order to eradicate any cancer cells without damage to nearby tissues. Because they are located near critical structures such as the brain and spinal cord, proton beam therapy is the most frequently recommended kind of radiation treatment. Proton therapy uses protons instead of X-rays to deliver precise, highly concentrated radiation directly to cancer cells without destroying the surrounding healthy tissue.

“The unique properties of proton therapy permit a sharper edge between the tumor that requires a higher radiation dose and the surrounding healthy tissue that needs to be spared,” says Dr. Gondi, who treats more than a dozen patients with chordomas in a typical year, referred from throughout the world.

“As we improve both our technology and our understanding of chordoma biology, we are harnessing both to enhance outcomes in our patients both in terms of tumor control, as well as their quality of life,” says Dr. Gondi.

Both Dr. Wolinsky and Dr. Gondi continue to explore new opportunities for treatment in their respective specialties. For example, 3D printed bones or carbon fiber implants could be used as potential substitutes for titanium reconstruction, which may help bones heal more quickly. Additionally, continued advances in proton therapy and the use of novel drug therapies during proton therapy may permit safer and more effective treatment.

Together, Dr. Wolinsky and Dr. Gondi offer patients at Northwestern Medicine Chordoma Center the most advanced treatment options, with coordinated care. And though chordomas are rare in the general population, they are not rare to these Northwestern Medicine specialists who are paving the way for better outcomes for patients.

### Symptoms:

- General weakness
- Double vision
- Headaches
- Impacted hearing
- Difficulty swallowing
- Speech and voice abnormalities

However, if your tumor happens to be located along the spine, you may experience:

- General weakness
- Pain in the legs
- Back pain
- Loss of bladder or bowel control



**Dr. Vinai Gondi, MD**

## Miss Illinois USA 2018: Melanoma Survivor

When you think melanoma, you likely think of moles. For Miss Illinois USA 2018 Karolina Jasko, it started with a manicure.

“I was a senior in high school and getting my nails done almost twice a month with a gel that uses UV light to set,” says Karolina, now 21. “I noticed what I thought was an infection on my right thumbnail — a black vertical line. I went to my primary care physician who referred me immediately to Northwestern Medicine.”

Karolina was diagnosed with subungual melanoma, which originates in the nail matrix and accounts for only 0.7% to 3.5% of melanoma cases worldwide.

Karolina’s mom survived melanoma twice. People like Karolina who have a first-degree relative with a history of melanoma have a 50% greater chance of developing it. Melanoma accounts for only 1% of skin cancer diagnoses, but it causes the majority of skin cancer-related deaths. Time is critical for diagnosis and treatment. *(Continued on next page)*



**Karolina Jasko, Miss Illinois USA  
2018**

### Using Her Platform to Promote Prevention

In her personal life, Karolina is not only the 2018 Miss Illinois USA, but also a part-time model.

She uses her prominence to promote melanoma prevention and screening alongside her mom, who shares her own stories as a melanoma survivor.

Karolina hopes people learn from her story. She advocates for safe exposure to UV rays.

## Miss Illinois USA 2018: Melanoma Survivor

“I was lucky enough to be diagnosed very quickly at Northwestern Medicine,” says Karolina. “What stuck out to me was how much everyone who took care of me truly cared about how I was feeling, while acting quickly.”

### Collaborative Care

Karolina’s diagnosis was a whirlwind of collaboration. Northwestern Medicine Dermatologist Pedram Yazdan, MD, saw Karolina immediately at Northwestern Medicine Lake Forest Hospital. He took a photo of her thumb and sent it to Northwestern Medicine Dermatologist Simon S. Yoo, MD, who saw Karolina urgently that same day at Northwestern Memorial Hospital and performed the initial surgery to remove the melanoma, alongside Northwestern Medicine Chief of Surgical Oncology Jeffery D. Wayne, MD. Northwestern Medicine Hand Surgeon Jason H. Ko, MD, MBA, then reconstructed Karolina’s thumbnail.

“Early detection and excision are vital to the treatment of melanoma, which is why we acted so quickly,” says Dr. Wayne, who is also Associate Director of Clinical Operations at Robert H. Lurie Comprehensive Cancer Center of Northwestern University. “In Karolina’s case, it was a team effort: The Surgical Oncology team removed the cancerous tissue from the nail matrix, and then Dr. Ko reconstructed the thumb with two additional surgeries.”

Dr. Ko showed Karolina a variety of thumb exercises that she practiced at home. With this type of therapy, she regained full function in her thumb.

“I still see Dr. Ko every time I have a concern, and he never takes my concerns lightly,” Karolina adds. “He also remembers the little details about my personal life, which makes me feel cared about every time I’m there.”

## Nathan’s Proton Therapy for Brain Cancer

A year after having surgery to remove a massive brain tumor, Nathan Darko’s symptoms returned. After a second brain surgery, Nathan was told he needed radiation therapy. That’s when his parents found out about proton therapy at Northwestern Medicine’s Chicago Proton Center -- a treatment option that changed Nathan’s life. “

### Year One: The First Tumor

His first tumor was discovered when Nathan was a senior in high school. He was healthy and active in cheerleading and baseball. A few months into his senior year, Nathan experienced the worst headache of his life. It became more and more persistent in time, until the pressure was unbearable and caused him to throw up.

Nathan was diagnosed with central neurocytoma, a rare type of a brain tumor located in the center of the brain.

Right after Thanksgiving, Nathan underwent a 7-1/2-hour surgery at a hospital in central Illinois to remove the tumor. Due to the massive size and location of the tumor, the surgery was more complicated than expected. *(Continued on next page)*



**Nathan Darko**

# Nathan's Proton Therapy for Brain Cancer

He lost a liter of blood, and he couldn't use the left side of his body. He spent the next several months working with rehabilitation specialists to learn how to read and write again as well as to build his strength for walking and using his hands. They also addressed cognitive issues, short-term memory problems and a change in his emotions.

## Second Surgery

Despite missing 50 days of school, Nathan recovered from the post-surgery complications in time to play on the baseball team and graduate on time with his high school classmates. He even made the collegiate cheer team at Illinois State University (ISU), where he started his freshman year that fall. But, a few weeks after moving into the dorm at ISU, his symptoms returned.

Some of the tumor was removed during a second, much shorter surgery in December. But after a few weeks of monitoring, Nathan's physician determined the tumor was still there and suggested radiation therapy. Nathan's parents started to research every option, and decided to look into proton therapy.

## Year Two: A Precise Treatment

During his initial visit to Northwestern Medicine's Chicago Proton Center, Nathan immediately felt at ease with the comfortable environment and friendly staff. He met with the Dosimetry team who created his customized treatment plan and a radiation therapist to be sized for the treatment mask. He also received a one-on-one consultation with William F. Hartsell, MD, FACR, FACRO, Medical Director of Northwestern Medicine's Chicago Proton Center.

Because of the size and type of tumor, proton therapy would target the tumor's multiple pieces by using a precise dose of radiation that conforms to the shape of the tumor. Only the spots in his brain with cancer would receive the radiation through pencil beam scanning, which minimized the damage to surrounding healthy tissue.

Right before he started proton therapy, Nathan tore his meniscus, requiring him to walk with crutches. Fortunately, Nathan was able to receive care for his knee at Northwestern Medicine Orthopaedics.

In December 2016, Nathan received the news of a lifetime: He was tumor-free. "We were in complete shock when we received the news. Proton therapy is remarkable. It completely disintegrated my tumor," Nathan says.

"I would go back to Northwestern Medicine in a heartbeat just knowing the type of people who are there and what they can offer," Nathan says.

"When I share my cancer journey with my students, they seem to try harder and appreciate things more. I tell them, you don't know what you can or can't do, until you can't do it anymore."

He has since graduated from college, bought his first house and landed a job teaching health and physical education, and coaching at a middle school in central Illinois. He also volunteers as a patient advocate for Northwestern Medicine's Chicago Proton Center where he mentors other patients, and shares his experience and support with people who are considering proton therapy.

## Message from Dr. Daniel Derman

*President, Northwestern International Patient Services  
Chief Innovation Officer and Sr. Vice President, Northwestern Memorial HealthCare*

We are excited to share with you the ongoing growth and developments at Northwestern Medicine. This newsletter highlights some of the recent news within our community and we hope that is helpful to you. If you have any questions, I welcome you to reach out to me or Laura Jaros, *Senior Practice Manager* at Northwestern International Health ([laura.jaros@nm.org](mailto:laura.jaros@nm.org)).

