

# Children's Center Update

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## Pediatric Sleep Medicine Integrates With Multidisciplinary Clinics To Facilitate Communication and Treatment

Sleep concerns are common in all children, but often more so in those children who are part of special populations or those with medically complex needs. As confirmed by a study published in *Pediatrics* in 2012, obstructive sleep apnea (OSA) in children is present in up to 5% of children. Up to 50% of children will have a sleep complaint at some point in their lives. Up to 10% of children will have difficulty with insomnia, as confirmed in 2006 in a study published in *Sleep* and 2014 in a study published in the *Journal of Pediatric Psychology*.

"OSA and other forms of sleep-disordered breathing are even more prevalent in certain special populations and other comorbid sleep difficulties can also be present," says Julie M. Baughn, M.D., a pediatric pulmonologist at Mayo Clinic's campus in Rochester, Minnesota. "Most children with OSA will benefit and their OSA may often be resolved by undergoing adenotonsillectomy. Many special populations may need additional surgeries or require the use of positive airway pressure. Mayo Clinic's Center for Sleep Medicine team recognizes the need for multidisciplinary care in these children, to treat a multitude of sleep concerns."

Children with genetic disorders such as Down syndrome (trisomy 21), Prader-Willi syndrome, Angelman syndrome and achondroplasia; neuromuscular disorders such as muscular dystrophy, myotonic dystrophy and spinal muscular atrophy; cerebral palsy; and spina bifida are all at increased risk of OSA as well as other forms of sleep-disordered breathing. As noted in a study published in *Sleep* in 2011, these children require polysomnography to diagnose and treat the sleep-disordered breathing.

"Children with autism, Angelman syndrome or neurodevelopmental delay can have difficulty going to sleep and staying asleep. When children

have sleep difficulties it significantly impacts their caregivers and families. Sleep concerns impact the mental health, cognition and well-being of children," says Dr. Baughn.

### Children's sleep disorders impact caregivers and families, too

Mayo Clinic sleep medicine specialists recognize the multidisciplinary nature of sleep issues in children and the significant impact these issues have on the child's caregiver or family. Knowing the importance of communication, team members collaborate with physicians in multidisciplinary clinics at Mayo Clinic Children's Center, including the multidisciplinary Aerodigestive Clinic and neuromuscular clinic.

"The team recognizes the high risk of sleep-disordered breathing in children with spina bifida and cerebral palsy," says Dr. Baughn. "When treatment for OSA is considered, the best therapy for the child can be discussed, as there is open communication between the sleep specialist and the child's other providers. The ability of the sleep specialist to not only provide diagnostic interpretation of a polysomnography, but to provide a comprehensive sleep consultation is an asset that allows patient and family-centered treatment of patients and their families."

"Our sleep medicine team works closely with endocrinologists in children with Prader-Willi syndrome who require polysomnography before and after initiation of growth hormone. We work with neurologists and pulmonologists in children with spinal muscular atrophy who are receiving nusinersen, a new genetic modifying treatment. Treatment for OSA in children is typically multidisciplinary and involves the expertise of an otolaryngologist."

The multidisciplinary model facilitates timely communication about treatment options. In the



Julie M. Baughn, M.D.

multidisciplinary Aerodigestive Clinic, the input of gastroenterologists, otolaryngologists, pulmonologists and sleep medicine specialists are all considered in the treatment plan given to a family.

Other multidisciplinary clinics at Mayo Clinic Children's Center may not see children at risk of OSA, but do see children with other sleep disorders. Mayo Clinic Children's Center has an active Angelman Syndrome Clinic, where children with Angelman syndrome will receive a sleep consult.

Children evaluated through the Adolescent Autonomic Dysfunction Clinic who are diagnosed with postural orthostatic tachycardia syndrome can have comorbid insomnia, delayed sleep phase syndrome and hypersomnia. Children seen in developmental and behavioral pediatrics, particularly those with attention-deficit/hyperactivity disorder and autism, have difficulty with insomnia and restless sleep.

"Mayo Clinic's team of sleep medicine specialists is committed and passionate about the team approach to sleep concerns in children," says Dr. Baughn. "That concern is never more important than in children with medically complex needs."

#### For more information

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## Multiple Options for the Treatment of Children With Epilepsy

Specialists at Mayo Clinic Children's Center in Rochester, Minnesota, are seeking innovations for children with epilepsy, while research teams are studying potential treatments, including new medications and surgical options. As a result, several cutting-edge options to eliminate or reduce seizures in children are available.

"Experts from various specialties are coming together to make decisions about medications and treatments," says Kai J. Miller, M.D., Ph.D., a neurosurgeon at Mayo Clinic Children's Center. "The research and clinical teams function seamlessly together. As a result, patients receive the most novel therapies to treat seizures and preserve brain function. Together, we're actively developing new technology."

#### Evaluation and treatment

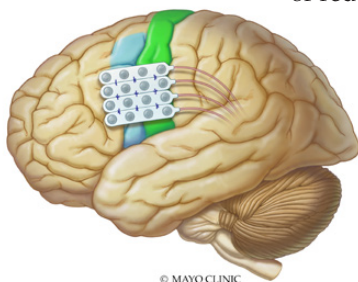
Mayo Clinic Children's Center has a pediatric team dedicated to the care of

children with epilepsy. After an initial evaluation, children and their parents can choose from a number of available options to reduce seizure frequency and severity.

"For some children with drug-resistant epilepsy, surgery is an option. But for others, a unique type of medication or diet therapy can decrease seizure frequency and severity," says Elaine C. Wirrell, M.D., a pediatric epileptologist at Mayo Clinic Children's Center and co-founder of the Pediatric Epilepsy Research Consortium.

#### Epilepsy surgery: Treatment when medicine doesn't work

Epilepsy surgery, which is considered when at least two anti-seizure medications have failed to work, removes or alters an area of the brain where seizures originate. As a Level 4 Comprehensive Epilepsy Center, the highest rating designated by the National Association of Epilepsy Centers, Mayo Clinic's multidisciplinary team



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**Figure 1.** Chronic subthreshold cortical stimulation utilizes electrodes that are surgically implanted at the location of seizure onset. The electrodes are connected to a generator implanted in the chest.

works to improve outcomes and reduce hospital stays through minimally invasive and advanced surgical techniques, including robotic guidance surgery.

"Using robotic guidance, surgeons can more precisely identify where seizures start," says Dr. Miller. "This allows us to target the seizures and stop them."

### Resective surgery

With resective epilepsy surgery, surgeons remove a focal area of abnormal brain tissue that generates seizures. Surgery is most often performed on either the frontal lobe, an area controlling motor and language function, or the temporal lobe, an area that controls memory, comprehension and emotions. In some children, resective surgery requires a larger operation. However, a much less invasive technique called laser interstitial thermal therapy may be an option for some children. In this technique, MRI is used to guide the surgeon to place a probe through a small hole in the skull. A laser pinpoints and destroys a small portion of brain tissue.

"This therapy actually burns and destroys the place in the brain where the seizure originates," explains Dr. Miller. "And it does so without injuring the rest of the brain or requiring a large surgery."

### Corpus callosotomy

Used in children who experience frequent drop seizures leading to repeated and abrupt falls, this surgery severs the bundle of nerves connecting the right and left sides of the brain. In most cases, the drop seizures are eliminated or markedly decreased, preventing ongoing injury.

### Hemispherectomy

Children who experience seizures that originate from multiple sites in one hemisphere often require a functional hemispherotomy. This surgery disconnects the abnormal, seizure-inducing hemisphere, allowing the other hemisphere to function normally and stopping the seizures.

### Neurostimulation treatments

Experts at Mayo Clinic Children's Center are also studying neurostimulation treatments for epilepsy, an alternative treatment for children with severe epilepsy or for those who cannot have surgery. This treatment applies electricity to the central nervous system with the goal of reducing seizure frequency and severity.

Some neurostimulation treatments are invasive, meaning they require a surgical procedure to implant a device. With these

treatments, an internal pulse generator or neurostimulator supplies electricity via an extension to implanted electrodes.

### Vagus nerve stimulation

Vagus nerve stimulation prevents seizures by sending regular, mild pulses of electrical energy to the brain via the vagus nerve. A stimulator device is implanted under the skin in the chest, and a wire is wound around the vagus nerve in the neck.

### Responsive neurostimulation

Responsive neurostimulation works by monitoring brain waves and responding to electrical activity that looks like a seizure to stop seizures before they cause clinical symptoms.

### Deep brain stimulation

Mayo Clinic is one of the leading sites in the country for deep brain stimulation implantation. This therapy delivers controlled pulses to a target in the brain that is part of a circuit involved in seizures.

### Chronic subthreshold cortical stimulation

In some cases, by the time a responsive device detects abnormal electrical activity, it might be too late to prevent a seizure. Subthreshold cortical stimulation provides continuous electrical impulses to an area of seizure onset to suppress the generation of the abnormal seizure discharge and thus attenuate the seizure (Figure 1, page 2).

An article co-authored by Dr. Miller and published in the October 2019 issue of *Brian Sciences* reported that chronic subthreshold cortical stimulation resulted in a progressive decline in the frequency of seizures in a group of 10 patients.

"The frequency of seizures and interictal discharges showed a progressive decline during continuous stimulation," the article states. Furthermore, the article highlights "a greater than 90% seizure reduction in two patients with a stimulation of the eloquent motor cortex for about one year."

### Transcranial magnetic stimulation

During a transcranial magnetic stimulation session, an electromagnetic coil placed against the scalp delivers a magnetic pulse that stimulates nerve cells in the brain (Figure 2).

### Transcranial direct current stimulation

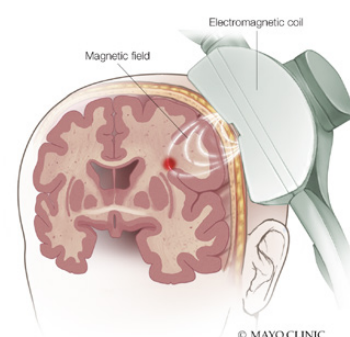
Transcranial direct current stimulation applies a low-intensity current that manipulates neuronal activity and neuroplasticity.



Kai J. Miller, M.D., Ph.D.



Elaine C. Wirrell, M.D.



**Figure 2.** Repetitive transcranial magnetic stimulation. In transcranial magnetic stimulation, an electromagnetic coil placed against the scalp creates a magnetic field that stimulates certain areas of the brain.





Katherine C. Nickels, M.D.

### Cutting-edge treatments and clinical trials

While surgical and neurostimulation treatments focus on seizure control, Mayo Clinic's multidisciplinary team of experts are researching cutting-edge drug treatments and participating in multiple clinical trials for the treatment of severe epilepsy syndromes. These include Dravet syndrome and Lennox-Gastaut syndrome, rare but severe epilepsy syndromes.

"As neurologists, we provide precision therapies through advanced understanding of etiologies and preferred treatments, such as potassium channel blockers for patients with potassium channel-related epilepsy encephalopathies and stiripentol and cannabidiol for patients with Dravet syndrome," explains Katherine C. Nickels, M.D., a pediatric epileptologist at Mayo Clinic Children's Center in Rochester, Minnesota. "While many of these therapies are considered to be new in most institutions, they are the standard of care here."

In an article in the September 2019 issue of

*CNS Drugs*, Dr. Wirrell and colleagues discussed promising results with drugs for Dravet syndrome, including stiripentol. "Stiripentol was associated with a greater than 50% reduction in convulsive seizure frequency in 71% of patients," their study showed.

In addition to focusing on medical treatments, the Mayo team provides holistic care for the child and family, addressing the learning and behavioral challenges that often are seen.

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## Mayo Clinic Specialists Team Up To Treat Rhabdomyosarcoma



Carola A S. Arndt, M.D.

Since the 1970s, there's been little or no change in the overall survival of patients with very high-risk rhabdomyosarcoma, according to a study in the July 2018 issue of *Cancer Treatment Reviews* co-authored by Carola A S. Arndt, M.D., a pediatric oncologist at Mayo Clinic Children's Center in Rochester, Minnesota.

For that reason, specialists at Mayo Clinic Children's Center are approaching treatment as a multidisciplinary team, offering cutting-edge treatments and research to improve the outcomes of children with rhabdomyosarcoma.

"We are blessed at Mayo Clinic to have an amazing team of people who are dedicated, talented and well versed in sarcoma surgery to give these kids the best chance at beating this rare cancer," says Patricio C. Gargollo, M.D., a pediatric urologist at Mayo Clinic Children's Center.

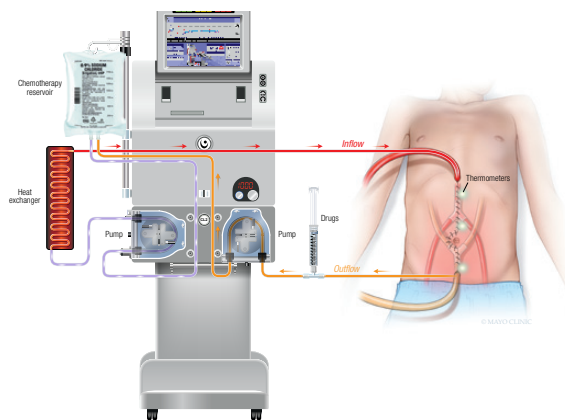
Specialists and subspecialists, including pediatric urologists, pediatric surgeons, orthopedic oncology surgeons, and radiation oncologists work together to create personalized, targeted surgical and radiation therapy plans for each child.

### Hyperthermic intraperitoneal chemotherapy allows for direct administration

One innovative and unique component of sarcoma care at Mayo Clinic includes hyperthermic intraperitoneal chemotherapy (HIPEC), one of only a few programs available in the country. HIPEC is a highly concentrated, heated chemotherapy solution administered directly into the abdomen during surgery, targeting any remaining cancer cells (Figure).



Patricio C. Gargollo, M.D.



**Figure.** Hyperthermic intraperitoneal chemotherapy (HIPEC) setup. HIPEC involves administration of a highly concentrated, heated chemotherapy solution directly into the abdomen intraoperatively after complete removal of all visible tumor.

### Proton beam therapy spares vital organs, healthy tissue

Mayo Clinic's Proton Beam Therapy Program uses pencil beam scanning, which allows oncologists to deliver higher doses of radiation to cancer cells while sparing healthy tissue. This targeted therapy is ideal for children with tumors close to vital organs that are still developing.

### 3D models enable surgeons, families to better understand tumor

Using data from a child's MRI or CT scan, pediatric radiologists create 3D models of the tumor. Models are brought into the operating room for reference during surgery, enabling surgeons to see exactly where to cut to remove the entire tumor or where radiation is needed. Parents also

can see the model before surgery to gain a better understanding of their child's tumor.

### Care that continues at home

Mayo specialists work together to ensure that care continues even when the patient goes home. "We work closely with the home oncologist or home primary care physician to coordinate care as appropriate," says Dr. Arndt. "This may be a continuation of chemotherapy with the home oncologist or support after chemotherapy."

### For more information

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## Teamwork, Technology Give Hope to Kids With Hand Anomalies

Mayo Clinic Children's Center in Rochester, Minnesota, is delivering hope to kids with congenital hand anomalies. Using a multidisciplinary approach along with sophisticated technology and groundbreaking clinical trials, specialists are able to address every aspect of care.

"The team brings broad experience with microsurgery, bone lengthening and straightening, free tissue transfer, and infant and pediatric prosthetics, which allows the best and most up-to-date care," says Steven L. Moran, M.D., a hand and plastic surgeon at Mayo Clinic Children's Center.

### Pioneering advances in technology

Specialists at Mayo Clinic Children's Center established a grading system and outcomes scoring assessment for children with absent or underdeveloped thumbs. These tools are now widely used in the U.S. and in Europe. Mayo Clinic uses the most advanced technology with regard to bone lengthening, soft tissue reconstruction and prosthetic fabrication, including 3D imaging and reconstruction, to manage congenital hand anomalies. Micro-computerized tomography (micro-CT) imaging enables greatly increased resolution on a small scale. Using an image from a micro-CT scan, pediatric radiologists can create 3D models that can be saved for further analysis.

Congenital hand differences can now be identified during fetal ultrasound, and consultation with the hand surgeon is often performed before a baby is born. Surgical models are made from imaging studies of the child's fingers and arms, allowing surgeons the opportunity to plan and practice

surgery. Dr. Moran, who has championed the use of microsurgery for the treatment of underdeveloped bones, described pediatric microsurgery as a successful procedure in an article in the April 2017 issue of *Clinics in Plastic Surgery*. According to Dr. Moran, this surgery can provide immediate reconstruction results without the need for tissue expansion, skin grafting or muscle sacrifice.

He further explains that Mayo Clinic is working to identify problems that may be repaired in utero. "We are working with new modalities in regenerative medicine in hopes of being able to regrow or restore hands and fingers and identify those problems that may be fixed before the baby is born," says Dr. Moran.

Mayo Clinic is also participating in FDA trials of an anti-scar medication to help minimize external signs of surgery.

"We take a multidisciplinary approach to manage congenital hand differences," says Nicholas A. Pulos, M.D., an orthopedic hand and microvascular surgeon at Mayo Clinic Children's Center. "As a team, we seek to provide the correct diagnosis to parents who are appropriately stressed and searching for answers in a single visit."

The treatment team includes two orthopedic hand and microvascular surgeons, as well as a pediatric orthopedic surgeon and a neurosurgeon specializing in peripheral nerve surgery.

### Integrated care that follows children into adulthood

Long-term, integrated care at Mayo Clinic Children's Center enables a level of care and trust



Steven L. Moran, M.D.



Nicholas A. Pulos, M.D.

that helps patients feel comfortable with their hand differences as they grow through different stages and phases of life.

"Our approach is to address every aspect of care — from diagnosis to treatment to emotional support — so the family feels well taken care of," says Dr. Pulos. "What sets Mayo Clinic Children's Center apart is our ability to consistently see these children as they grow into adulthood."

Dr. Moran agrees, stating, "We are participating in a clinical trial regarding anti-scar medications. These medications could help children heal with minimal external signs of surgery."

Processes are put in place as children return to their primary care physician to ensure consistent treatment. But, as Dr. Pulos states, Mayo Clinic is just a phone call away. "When needed, all of our specialists are here on campus, so families can see the right people quickly." "The future is definitely bright for children with hand anomalies."

#### For more information

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## Fetoscopic Repair of Myelomeningocele: A Minimally Invasive Option



Edward S. Ahn, M.D.



Rodrigo Ruano, M.D., Ph.D.

Mayo Clinic is among a handful of centers in the United States that offer fetoscopic repair of myelomeningocele. The procedure can provide surgical outcomes for the fetus that are similar to those of open surgery while lessening the risk of preterm birth.

"There's a big learning curve for this minimally invasive surgery, which we have met through extensive training and simulations. We believe that the challenge is worthwhile to achieve more full-term deliveries of these babies," says Edward S. Ahn, M.D., a neurosurgeon at Mayo Clinic in Rochester, Minnesota.

Open surgery has been the standard of care for prenatal myelomeningocele repair. Although the open procedure generally improves outcomes for children with myelomeningocele, it increases the risks of preterm birth and uterine rupture. Women who have open surgery for prenatal myelomeningocele repair must have a cesarean section for that pregnancy and all future pregnancies, as well as wait at least two years before becoming pregnant again.

"The objective of fetoscopic repair is to achieve the same outcomes for the babies but reduce maternal obstetric risks," says Rodrigo Ruano, M.D., Ph.D., chair of Maternal and Fetal Medicine at Mayo Clinic's campus in Minnesota. "After fetoscopic surgery these women will be able to have vaginal delivery during that pregnancy and any future pregnancies."

#### Large, multidisciplinary team

Fetoscopic myelomeningocele repair requires an integrated team of specialists. At Mayo Clinic, that team includes neurosurgeons with experience in intrauterine procedures, maternal and

fetal medicine surgeons, pediatric and adult anesthesiologists, pediatric cardiologists to continuously monitor fetal cardiology, and specialized nursing support. "We could not accomplish a successful intervention without this strong collaboration," Dr. Ruano says.

Myelomeningocele is generally diagnosed through routine fetal ultrasound during the second trimester of pregnancy. The surgery can be performed between 19 and 26 weeks of gestation. "We usually prefer to do the procedure at around 24 or 25 weeks, when the fetus is a little bit bigger," Dr. Ahn says.

The fetoscopic procedure takes about 2.5 hours. General anesthetic is first given to the mother. That anesthetic relaxes the uterus and the fetus before the fetus receives intramuscular pain medication. Carbon dioxide is inserted into the uterus to improve visualization of the spinal defect. The repair is performed by inserting 2-millimeter instruments through tiny ports (Figure, page 7).

Babies who have prenatal myelomeningocele repair generally experience fewer complications than do babies who have postnatal treatment. Prenatal repair reduces the incidence of Chiari malformation, which can occur when cerebrospinal fluid leaks through the myelomeningocele.

"The Chiari malformation will not reverse without intervention," Dr. Ruano says. "But we have an 80% to 90% chance of reversal if the myelomeningocele is fixed in utero."

Chiari malformation can lead to hydrocephalus. "The increase in prenatal myelomeningocele repair has dramatically reduced the incidence of hydrocephalus in these babies," Dr. Ahn says. "Only about 40% of babies with

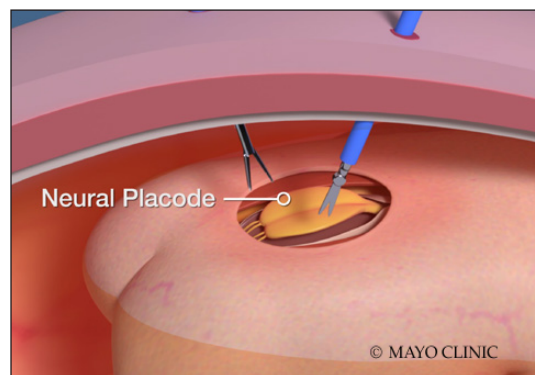


myelomeningocele require treatment for hydrocephalus, compared with 80% previously."

Prenatal repair also prevents the spinal cord's exposure to amniotic fluid, which may be toxic to the spinal cord. "In the long term, babies whose myelomeningoceles are closed prenatally tend to have better leg function," Dr. Ahn says.

Mayo Clinic's obstetric and pediatric specialists have experience caring for babies born with myelomeningocele. The Cerebral Palsy/Spina Bifida Clinic on the Minnesota campus coordinates care for children and teenagers with spina bifida.

"Mayo Clinic is structured to provide multidisciplinary care," Dr. Ahn says. "From simple matters such as scheduling appointments to the routine conferring of specialists, everything is well coordinated."



**Figure.** Illustration shows fetoscopic repair of a myelomeningocele.

## The Mayo Clinic Pediatric Fertility Preservation Program

Childhood cancer management requires multidisciplinary care to mitigate long-term health consequences while maximizing chances of a complete cure. The Mayo Clinic Pediatric Fertility Preservation Program, a part of the Mayo Clinic Children's Center, is one of two programs in the upper Midwest offering both ovarian and testicular tissue cryopreservation to children under Institutional Review Board-approved research protocols.

Asma J. Chattha, M.B.B.S., with Pediatric Gynecology at Mayo Clinic in Rochester, Minnesota, a co-founder of the Pediatric Fertility Preservation Program, notes: "As childhood cancer survival rates have improved, reaching upwards of 80% for the first time in decades, concern pertaining to long-term survivorship is growing. Research shows that fertility preservation counseling, particularly in pre-pubertal children, is not occurring frequently enough, despite being a key quality-of-life indicator for survivors."

While post-pubertal males can undergo sperm cryopreservation and post-menarchal females, if time allows, can proceed with egg (oocyte) cryopreservation, options for pre-pubertal children are not clinically available.

"The Mayo Clinic Pediatric Fertility Preservation Program was established in 2016 as a multidisciplinary effort: It brings together the expertise of Pediatric Fertility Preservation Program to discuss next steps," explains Carola A. S. Arndt, M.D., with Pediatric Hematology/Oncology at Mayo Clinic in Rochester, Minnesota.

Siobhan T. Pittcock, M.B., B.Ch., with Pediatric Endocrinology at Mayo Clinic in Rochester, Minnesota, expands, "Depending on the age,

gender and pubertal status of the child, fertility preservation protocols are discussed."

"One of the unique aspects of the Pediatric Fertility Preservation Program is its inclusion of indications other than oncologic conditions that could impair fertility, such as Turner or Klinefelter syndrome; nephrologic and rheumatologic conditions requiring gonadotoxic therapy; and transgender youth," expands Candace F. Granberg, M.D., with Urology at Mayo Clinic in Rochester, Minnesota. Dr. Granberg is a co-founder of the Pediatric Fertility Preservation Program.

Both ovarian and testicular tissue cryopreservation protocols remain experimental. However, over 130 live births have been reported from ovarian tissue reimplantation following conclusion of treatment.

"It is estimated that hormone function returns as a result of ovarian tissue reimplantation in over 90% of cases. It is difficult to determine the actual percentage of success of fertility potential returning after ovarian tissue reimplantation, but estimates run between 30% and 52%," clarifies Zaraq Khan, M.B.B.S., with Reproductive Endocrinology & Infertility at Mayo Clinic in Rochester, Minnesota. Dr. Khan is also a co-founder of the Pediatric Fertility Preservation Program.

Testicular tissue cryopreservation has not yielded live births in humans, but success has been achieved in rodents and primates with recent production of functional sperm and birth of healthy offspring after autologous grafting of cryopreserved pre-pubertal testes in rhesus macaques.

"In vitro maturation of immature oocytes is currently being explored under research protocols at Mayo Clinic, hopefully expanding fertility



Asma J. Chattha, M.B.B.S.



Candace F. Granberg, M.D.



Zaraq Khan, M.B.B.S.

**Medical Editor:**  
Sherilyn W. Driscoll, M.D.

**Contributors:**  
Edward S. Ahn, M.D.  
Carola A.S. Arndt, M.D.  
Julie M. Baughn, M.D.  
Asma J. Chattha, M.B.B.S.  
Patricio C. Gargollo, M.D.  
Candace F. Granberg, M.D.  
Zaraq Khan, M.B.B.S.  
Kai J. Miller, M.D., Ph.D.  
Steven L. Moran, M.D.  
Katherine C. Nickels, M.D.  
Nicholas A. Pulos, M.D.  
Rodrigo Ruano, M.D., Ph.D.  
Elaine C. Wirrell, M.D.

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## Contact Us

Mayo Clinic welcomes inquiries and referrals, and a request to a specific physician is not required to refer a patient.

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## Resources

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medical-professionals**

Clinical trials, CME, Grand Rounds,  
scientific videos and online referrals



preservation options from ovarian tissue in the future," announces Yulian Zhao, M.D., Ph.D., with Reproductive Endocrinology & Infertility and director of the Fertility Testing Laboratory at Mayo Clinic in Rochester, Minnesota.

### The process of ovarian and testicular tissue cryopreservation

"After discussion and completion of the informed consent process, preservation of ovarian tissue for future fertility or hormone replacement is performed via a laparoscopic unilateral oophorectomy," explains D. Dean Potter Jr., M.D., chair of Pediatric Surgery at Mayo Clinic in Rochester, Minnesota.

"This is coordinated with clinically indicated medical procedures such as central line placement or biopsy in order to reduce anesthesia-related risks and costs," adds Vidhu B. Joshi with Urology Research at Mayo Clinic in Rochester, Minnesota.

"Following removal of the ovary, a pathologist examines the tissue to exclude presence of malignant cells. The tissue is prepared into strips from the ovarian cortex by the fertility lab team," elaborates David L. Walker with Reproductive Endocrinology & Infertility at Mayo Clinic in Rochester, Minnesota.

"Testicular tissue cryopreservation entails a biopsy or wedge resection of one testicle, with care taken to avoid asymmetry," says Patricio C. Gargollo, M.D., with Urology at Mayo Clinic in Rochester, Minnesota.

For both ovarian and testicular tissue cryopreservation, the majority of the tissue (80%) is saved for future use by the patient, and the remainder de-identified for research purposes. Storage costs are \$250 a year. Infectious agent screening for hepatitis B and C viruses as well as human immunodeficiency virus required by the Food and Drug Administration is completed prior to the procedure.

Monitoring occurs one week after surgery and then annually thereafter to assess for emergence of adverse events as well as patient and family satisfaction. As part of clinically indicated surveillance, children are monitored for hormonal deficiency through

anthropomorphic measurements, growth velocity curves and Tanner staging.

### Early results from the Pediatric Fertility Preservation Program

Overall, childhood cancers represent more than 90% of the fertility-threatening conditions in this group, while other indications such as aplastic anemia and transgender identity are less frequent. The most common indications in males are hematologic malignancies (56%) such as lymphomas and leukemias, whereas rhabdomyosarcomas or other sarcomas (45%) are most common in females. The median age of male and female participants is 9 years (range 0.92 to 14 years) and 11 years (0.83 to 17 years), respectively.

### Patient satisfaction with cryopreservation procedure

Ovarian and testicular tissue cryopreservation procedures have been well tolerated without adverse events. High levels of satisfaction were reported during follow-up surveys; 90% of patients and families feel confident recommending the program to another parent. The future availability of this option for their child was rated as the most positive aspect of the decision to proceed with cryopreservation.

The Pediatric Fertility Preservation Program offers both ovarian and testicular tissue cryopreservation options for individuals undergoing cancer therapy or facing other fertility-threatening conditions or treatments, to preserve reproductive potential in a timely manner regardless of pubertal status.

### For more information

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Fertility Testing Laboratory. Mayo Clinic.  
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4500 San Pablo Road  
Jacksonville, FL 32224

200 First Street SW  
Rochester, MN 55905

13400 East Shea Boulevard  
Scottsdale, AZ 85259

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