Pediatric Liver Diseases and Transplant Program
A leader in the treatment of pediatric liver disease

We offer the complete spectrum of care for pediatric liver disease, from evaluation and medical management to cutting-edge surgery and transplant procedures.

If your child has been diagnosed with a serious liver disease, receiving care from an expert, integrated, multidisciplinary team with experience treating patients with complex liver disorders is the key to helping them live a long, healthy life.

A leader in pediatric liver transplantation

<table>
<thead>
<tr>
<th>Hospital/Location</th>
<th>Living Donor Transplants in a Year</th>
<th>Deceased Donor Transplants in a Year</th>
<th>Getting a Deceased Donor Transplant Faster</th>
<th>One Year Liver Survival</th>
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<tbody>
<tr>
<td>MedStar Georgetown University Hospital*</td>
<td>5 Children</td>
<td>24 Children</td>
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<tr>
<td>Center at 36.9 miles</td>
<td>2 Children</td>
<td>4 Children</td>
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<td>Center at 99.9 miles</td>
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**Transplant centers performing 1 or more.

Trust us to provide the care you need, safely.

We have established clean, secure care environments. Your health and safety are always our top priority.

- Face masks required for everyone, regardless of symptoms
- Frequent disinfecting and cleaning
- Chairs in public spaces are positioned for physical distancing
- Staggered appointments to minimize people in a given area
- Sanitizing stations throughout every facility

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MedStarHealth.org/Safe
Autoimmune liver disease

Dvir, age 12

On any given day, you could find then 12-year-old Dvir running around, playing basketball with friends, or playing games on his phone. Then one day he stopped eating, and was vomiting frequently.

“He was so weak, he didn’t even want to play on his phone,” his mother Julie remembers. He was jaundiced, very weak, and sleeping most of the time.

At the Transplant Institute, Dvir was diagnosed with acute liver failure from autoimmune hepatitis, a rare condition that causes the immune system to attack and damage the liver. In this case, transplant was not the first line option, and treatment with steroids lowered the activity of his immune system, thus avoiding the need for a transplant.

“He was in the hospital for several weeks before he stabilized. The doctors, nurses, and child life staff were great. Dvir is now 17 and healthy, with normal liver function,” Julie adds.

Avoiding Transplant When Possible

Care tailored for each child

The MedStar Georgetown Transplant Institute team partners with our local and regional pediatric colleagues to offer state-of-the-art pediatric hepatology care. The primary goal of the care we provide is to avoid or delay the need for a liver transplant.

Our experienced pediatric hepatology team completes a timely evaluation and creates a treatment plan that includes the latest treatment options for acute and chronic liver disorders and the complications they cause.
Biliary atresia: live donor transplant

Ashlynn, age 9 months, living related donor transplant recipient

Six-month-old Ashlynn was living in England with her family when she was diagnosed with biliary atresia, a rare congenital defect of the liver ducts. Doctors there performed a Kasai procedure. When she failed to respond to treatment, Ashlynn, her mother and father, a physician in the U.S. military, were shipped stateside to MedStar Georgetown Transplant Institute. Ashlynn was immediately put on the national organ donor waiting list, but she continued to get sicker by the day.

“You can’t believe it’s happening,” says her mother Arielle. “All of a sudden, your beautiful baby needs a new liver before time runs out.”

Tests showed that Arielle was a match for Ashlynn, so she donated a portion of her liver to save her then 9-month-old baby.

Today Ashlynn is a happy, healthy young girl.

We offer the complete spectrum of options and we care for the youngest, smallest patients

- Our current team has managed children with liver disease for over 15 years and performed more than 470 liver transplants in children under the age of 18.
- Half of those transplants were in children less than a year old and 25 percent of our transplant patients were younger than six months and weighed less than 6 kg.
- Our program is one of four in the nation and the only one in our area to tackle those challenging pediatric cases.

The conditions for which we offer transplant

We care for children with all types of liver-related disorders, including:
- Acute liver failure
- Chronic liver disorders
- Liver tumors
- Metabolic liver disorders

Variety of transplant options

- Living donor liver transplants from related and unrelated/altruistic donors
- Deceased donor whole or anatomically reduced liver transplants
- Deceased donor split-liver transplants
- Domino liver transplantation

National Leader in Transplants for Children Under One Year Old
The MedStar Georgetown Metabolic Transplant Program is a unique partnership that brings experts together. Through our partnership with the Rare Disease Institute at Children’s National Hospital, we provide expert care and support for children with metabolic disorders. We are one of only four such programs in the nation.

We are changing the paradigm of transplantation through integrative treatment

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Propionic acidemia

Charlotte, age 2 ½, transplant for metabolic liver disease

Something didn’t seem right to first-time parents Kathleen and Chris. Their newborn daughter Charlotte was lethargic and not feeding well. “One night, a few days after we brought her home from the hospital, it was difficult to wake her,” remembers Kathleen. “Her skin felt chilly and her temperature was below normal.”

Charlotte was diagnosed with a rare genetic disorder called propionic acidemia, which prevents the body from processing certain parts of proteins properly. This causes a build-up of toxins in the blood and tissues leading to brain and vital organ damage and, if left untreated, death. Genetic testing confirmed the diagnosis.

Concerned, Kathleen researched propionic acidemia. She discovered a few children had undergone liver transplants as an experimental treatment. “No hospital in our area was willing to try this,” explains Kathleen, “so I called academic medical centers looking for someone who would. Dr. Kim Chapman, a propionic acidemia expert at Children’s National Hospital in Washington, D.C., recommended the MedStar Georgetown Transplant Institute.”

When she was 2 ½, Charlotte underwent a successful transplant. Today, her diet is normal and she has had no more metabolic crises. “Her life and ours is so much better. The transplant saved her life many times over,” says Kathleen.

Charlotte underwent a successful liver transplant. Here she poses as a budding magician.
Maple syrup liver disease

Korey, age 6, domino transplant donor

First-grader Korey was born with Maple Syrup Urine Disease (MSUD)—a rare metabolic disorder that can cause coma, seizures, brain damage, even death. A new liver would stabilize his condition.

Meanwhile, middle-aged Isobel knew she would die if she didn’t soon get a new liver to replace her failing one.

Both got what they needed on the same day, in the same place, thanks to the MedStar Georgetown Transplant Institute.

In a coordinated, domino procedure, Korey received a liver from a deceased donor, then his liver was transplanted into Isobel. Adds Isobel, “Thanks to this beautiful little boy, I have a second chance at life.”

When one gift can save three lives: Domino transplantation

A pioneer in using transplantation as a precautionary treatment for children with MSUD, the Institute is also at the forefront of transplanting those MSUD livers into patients with liver failure through domino transplantation.

To help ensure that as many patients in need as possible benefit from liver transplantation, we take our responsibilities for organ sharing seriously, performing transplants that maximize the number of patients who benefit from a single liver graft.

We have performed domino liver transplantation in patients with MSUD, including one of the first toddler recipient and split liver domino transplants.

In October 2015, MGTI became one of the first to perform a combined split liver and domino transplant, effectively saving three lives with two organs. A 36-year-old received the lion’s share of the deceased donor liver, while the smaller portion was reserved for a 1-year-old with MSUD. That infant’s liver was then transplanted into another baby born with biliary atresia. The combined procedures took a team of more than 20 people 12 hours to complete.

One of the World’s First Double Cascade (Combined Split Liver and Domino) Transplants

A. Donor liver saved three lives with two organs. (12-hour procedure with 26-person surgical team.)
B. A 36-year-old received part of a deceased donor liver.
C. A smaller portion went to an infant with Maple Syrup Urine Disease.
D. The infant’s liver went to a baby with biliary atresia and functioned normally.

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Hepatoblastoma

Blake, age 9 months, deceased donor split liver transplant recipient

Blake arrived much earlier than his mother Rebecca expected. Born in her 23rd week of pregnancy, Blake weighed only 1 pound 7 ounces and spent his first months in the NICU battling a range of complications. As his parents were preparing to bring him home, an ultrasound to check on the health of his kidneys found a mass in his liver. He was diagnosed with hepatoblastoma, a rare, cancerous tumor that affects young children.

“We were in shock,” Rebecca remembers. “There were no symptoms. We were expecting to finally bring our baby home, but instead we moved from the NICU to the oncology department and started chemo for an unresectable hepatoblastoma.”

Blake underwent four rounds of chemotherapy to shrink the tumor and prevent the cancer from spreading. Because of where the tumor was located, his doctors felt he was a good candidate for a liver transplant and referred him to the Transplant Center for Children at MedStar Georgetown Transplant Institute. His parents weren’t a match for the transplant, so Blake was placed on the waiting list for a donor liver and continued chemotherapy.

At nine months, Blake underwent a successful deceased donor split liver transplant. Recently he started Pre-K, a milestone his parents couldn’t have imagined just a year ago. “When I was holding that 1 pound 7 ounce baby in my arms, I didn’t know what his future would hold. When I look at how well Blake is doing now, it’s amazing,” adds Rebecca.

Taking on liver tumors

Pediatric liver tumors are rare and require a unique surgical expertise:

- We offer complex liver resection for pediatric liver tumors.
- When needed, we offer liver transplantation performed with a multidisciplinary team approach.
We are committed to:
• Superior quality of care for every patient
• Individualized family and patient centered care
• Safety and transparency
• Excellence in teaching and mentoring
• Innovation and leadership through local, national, and international research

Our team includes:
• Pediatric hepatologists and transplant specialists
• Fellowship-trained liver and transplant surgeons
• Transplant pharmacists
• Pediatric anesthesiologists
• Pediatric nurses and nurse practitioners
• Nutritionists
• Child life specialists
• Social workers

Understanding the transplant process

Step 1: Evaluation
The pretransplantation evaluation is done to determine the severity of your child’s disease, whether the condition can be medically or surgically managed, and whether your child is a candidate for transplantation. Pretransplantation testing includes a general health assessment; testing for blood clotting disorders, infectious diseases, brain, heart, kidney, and lung function; imaging of the abdominal and vascular anatomy; and education and a support plan to help prepare you to care for your child during and after the transplant.

Step 2: Determining if your child is a candidate for transplantation
After the evaluation, your child’s case is presented to the transplant selection committee. If the committee agrees that transplantation is the appropriate treatment, your child will be placed on the United Network for Organ Sharing (UNOS) waiting list.

Step 3: Waiting for a new organ
The transplant team will closely monitor your child’s condition in coordination with your primary care physician as you wait for an organ to become available. You will receive ongoing education about your child’s condition and about transplantation.

Step 4: Transplantation
When an organ becomes available, your child will be admitted and undergo transplantation surgery and recovery, first in the intensive care unit, then on the pediatric transplant unit in the hospital.

Step 5: After the transplant
While your child is recovering, your family will complete the transplant education program. When your child is discharged from the hospital, the transplant team will continue to closely monitor your child in our outpatient clinic. Labs will be drawn every 2 months. Usually about three months after the transplant, most of your child’s care is transitioned to your child’s primary care doctor and gastroenterologist, with follow-up every 3 months. Your child will continue to be seen by the transplant team on a yearly basis or as needed to monitor his or her condition.

Keeping Patients Connected to Their Referring Physicians
We work closely with our referring colleagues and your local care team before, during, and after transplantation.

Expert care from leaders in pediatric liver disease
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A comprehensive team in a family-oriented setting

Our dedicated unit offers the latest technology in a caring, family-focused setting designed to ease your child’s anxiety about being in the hospital. Patients have access to a play area, as well as recreational and therapeutic activities, all in a child-friendly setting, and under the guidance of our experienced child life staff.

The Pediatric Liver Disease and Transplant Team

Our team includes some of the leading experts in the field of pediatric liver disease and transplantation.

Help and hope are a call away

To learn more about how the MedStar Georgetown Transplant Center for Children can help your child, call 202-444-3700/0395 or visit MedStarGeorgetown.org/Transplant.

MedStar Georgetown Transplant Institute Locations

The MedStar Georgetown Transplant Institute provides diagnosis and treatment for pediatric patients at MedStar Georgetown University Hospital and Children’s National Medical Center.

1. MedStar Georgetown University Hospital
   3800 Reservoir Rd., NW
   2nd Floor PNC
   Washington, DC 20007

2. Children’s National Medical Center
   111 Michigan Ave., NW
   Washington, DC, 20010