

‘Giving Hope...Making Miracles

The Sornsins are one of many families COTA has helped over its 25 years



In 1992, Ben Sorsin went from health to hepatic coma in only 10 days. He was in the ICU and only hours from death when a liver was donated.

Liver recipient Ben Sorsin is a college sophomore and honors student majoring in criminal justice.

BY KIM CARTER PARKER

Eighteen years ago, Thomas and Jodi Sorsin of Tempe, Ariz., were desperate for a miracle. Ben, their 2-year-old toddler, needed a liver transplant to survive.

Adding to the pain and stress of a critically ill child was the fact that Ben's illness, diagnosis and transplant came as a complete surprise. Many transplant families have time to prepare, but the Sornsins did not.

On New Year's Eve 1992, Ben came down with a cold. Two weeks later, he was fighting for his life.

What happened? Ben was diagnosed with complete liver failure due to a virus of unknown origin. In a matter of only 10 days, Ben went from being a healthy toddler to a sick child in a hepatic coma.

"Ben was in the ICU," Jodi remembers, "and only hours away from death. Then, we received the news that a liver had been found, and he would be transplanted the next morning...a true miracle." While Thomas and Jodi were living at Ronald Reagan UCLA Medical Center in Los Angeles to care for Ben, they were confronted with the financial reality of Ben's transplant.

Their health insurance was going to cover only about \$100,000 of the transplant bill. Jodi remembers being called to the hospital's finance office repeatedly and asked how they were going to pay the medical bill. Neither Thomas nor Jodi knew how that was going to happen.

They needed help, and they needed it quickly.

CALLING COTA

Meanwhile, friends and family members started asking how they could help this young family, and one friend introduced the Sornsins to the Children's Organ Transplant Association (COTA).

"I made the call to COTA as soon as we heard about this amazing organization," Jodi says. "The person on the other end of the phone told me not to worry about the money—COTA would help us.

"Once COTA was on board, and our team of volunteers started a fund-raising effort, we were never again called to the hospital's finance office," Jodi said. Their second miracle? According to Jodi, it was being able to concentrate on their baby's recovery and not worry about the mounting bills.

A team of volunteers made up of family members, friends and co-workers from Hunter Contracting, where Thomas was employed, began working with COTA's team of professionals almost immediately to launch a fund-raising effort with a goal of raising \$200,000.

"It was amazing how people came forward to help because they saw Ben's photo on TV or on a collection canister," Jodi recalled. "One man, a stranger to our family, saw Ben's photo and led efforts that raised \$45,000."

'GIVING HOPE...MAKING MIRACLES'

"Giving hope and making miracles is more than COTA's slogan—it is our guiding vision," said Rick Lofgren, president of COTA.

"The Sornsins' story is, unfortunately, all too common...a child who needs a transplant, combined with financial issues jeopardizing that child's life and the family's future.

"The miracle," Lofgren added, "is the community that works together to give a family hope."


COTA was founded in 1986 when a baby boy from Bloomington, Ind., needed a liver transplant. The community rallied and raised more than \$100,000.

Even though the child died before a liver became available, their efforts were not in vain. That core group of volunteers became the founders of COTA.

When COTA celebrated its 25th anniversary in April, Ben was 20 years old. He is 6'3"—and healthy. A college sophomore, he is working toward a degree in criminal justice.

Ben Sornsins is a miracle—thanks to the selfless gift of liver donation. And thanks as well to the hundreds of Arizona volunteers who worked with COTA to make sure a sick little boy had the chance to become a healthy and happy adult.

"When your child is dying and you need a miracle, COTA is there for you," Jodi said. "All those years ago, our hope was that we would one day have a normal life.


"And now, 20 years later," she added, "we are a normal—and very thankful—family." 

Kim Carter Parker is communications manager of the Children's Organ Transplant Association.

SELECTED HIGHLIGHTS

Over its 25 years...

- COTA has worked with more than 1,600 transplant families with overwhelming financial needs, and every family has received no-cost assistance.
- COTA has raised nearly \$60 million, with more than 150,000 people donating time and resources to help transplant families.
- COTA began working with young adults with single cell genetic disorders requiring a transplant in 1992. COTA has provided assistance to more than 300 young adults.
- COTA's firm commitment to providing services free of charge has never wavered.
- COTA's only qualifying criteria are age, legal residence and status as a transplant patient.
- After a transplant patient begins work with COTA, they never get "too old" for COTA services.

 Visit cota.org for more information about COTA and its services.

FREE POLICY BROCHURES

Were you aware that UNOS has available a multitude of brochures and other resources for candidates and transplant professionals that explain various organ allocation policies?

Written in plain language and often available in both English and Spanish, the resources below are currently available. You can download a single copy from the UNOS website or order multiple print copies from UNOS' online store.

Q&A about Lung Allocation Policy

[candidate and professional versions]

A recent update includes information on pediatric priority for lung allocation, which reflects policy changes implemented in summer 2010. Also explains the lung allocation score (LAS) and required data.

MELD/PELD

[English and Spanish versions]

Learn more about the numerical scores currently used to allocate livers

Expanded Criteria Donor Kidneys

[English and Spanish versions]

Read about how less commonly used kidneys are allocated


Multiple Listing


[English and Spanish versions]

Contains information for transplant candidates who want to list at multiple centers—includes a tear-off consent form for use in medical records to demonstrate your center's compliance with OPTN multiple listing policy.

Calculated Panel Reactive Antibody (CPRA)

[candidate and professional versions]

Learn more about CPRA and its importance in organ transplantation. Downloadable only. 

 To view and/or download policy brochures, visit unos.org (*donation and transplantation > professional education > policy brochures*). Quantities can be ordered from UNOS' online store at <http://store.unos.org>.