
A Rare Disorder. A Family's Faith.

Helmets & Helpers

Samatha's parents find hope in doctors with a custom-fitted piece of plastic and several pilots with halos

Headband designed to reshape Sam's skull

By Anne Hart

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Miki and Dave Allgire noticed the curious looks given to their daughter, Samantha, after she was born.

But lately their baby's misshapen head is less likely to draw stares.

"There are people who meet her who don't know right away," Dave said.

The Allgires credit a custom-made, 6-ounce pink helmet Sam has worn day and night for about a month as a low-risk alternative to surgery.

The custom-fitted plastic helmet with an open top and foam lining was developed by a team of engineers and doctors to apply gentle pressure to Sam's head. The goal is to correct the deformity caused by a hole Sam had in her head in-utero.

This disorder, called an encephalocele, was caused by a defect in the fusion of the cranial bone and required surgery immediately after birth. It left Sam with a pointy head.

Sam's helmet is called a Dynamic Orthotic Cranioplasty, or DOC Band, made by Arizona-based Cranial Technologies Inc. and approved by the U.S. Food and Drug Administration.

The company has 19 clinics and has seen a 226 percent increase over five years.

The process of making Sam's helmet began in the company's Atlanta clinic near Northside Hospital. A cast of her head was made and sent to Tempe, Ariz., where technicians carefully mold the band.

Helmets are increasingly being used to reshape babies' heads, some for serious health problems like Samantha's, but others for skull deformities that can be prevented.

Deformities such as positional plagiocephaly, or flat head, have increased sixfold since the "Back to Sleep" campaign began, WebMD reported in 2000.

This occurs when babies sleep exclusively on their backs and have consistent pressure on their soft, forming skulls.



His baby daughter needed a personalized touch for her helmet, so Dave Allgire painted it pink, added an angel and wrote Samatha's name on it.

SAM'S PINK HELMET

Samatha's helmet is called a Dynamic Orthotic Cranioplasty, or DOC, Band. The lightweight plastic bands apply gentle pressure to the heads of infants. These mild pressures are applied to capture the growth of the infant's head, holding growth in the prominent areas and encouraging it in the flat regions. Adjustments are made to the band weekly or bi-weekly. Each helmet costs \$3,000.

SAMATHA FUND

Donations can be made to:
The Samatha Allgire Fund
P.O. Box 61629
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As a result, they develop flat spots on their heads.

A national American Academy of Pediatrics campaign began in 1992 that urged parents to have their infants sleep on their backs to decrease the risk of sudden infant death syndrome (SIDS).

The campaign has cut the SIDS rate by more than 40 percent.

But that obvious benefit has a side effect: a marked increase in cases of positional plagiocephaly. About 90 to 95 percent of the helmets made by Cranial Technologies are to correct positional molding of the head.

Although that disorder is usually resolved by time and Mother Nature, in some severe cases, doctors prescribe helmets.

The deformity can be prevented by having babies spend supervised time on their tummies so their muscles exert more muscle action.

Experts recommend placing them on their stomachs when they are awake and supervised; or putting children to sleep on their backs in varying places in the room, so their attention will be drawn in different directions; and limiting time in car seats and other infant carriers.

Head deformities in babies also are on the rise because of premature births, restricted in-utero space due to multiple births and mothers in their 30s and 40s giving birth for the first time so their offspring have to fight against their tight uterus.

Children with plagiocephaly usually wear helmets about 23 hours a day for an average of four and a half months.

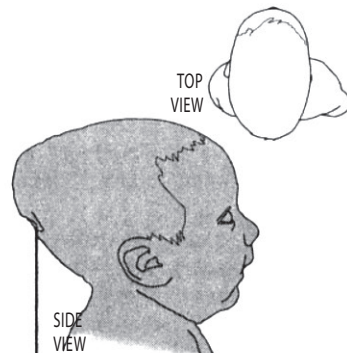
Tim Littlefield, a biomedical engineer and vice president of Cranial Technologies, said many skull deformities treated with helmets can be prevented.

"We overuse car seats and swings and bouncy seats," Littlefield said.

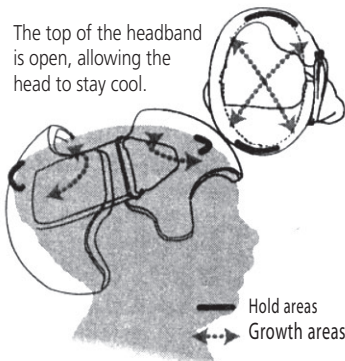
"Parents are so afraid of SIDS they leave them in the seats 24 hours a day. If we can get the word out about the importance of supervised tummy time, we all win because we don't need to be treating as many of the deformities as we do."

Redirecting growth

Cranial Technologies, developer of DOC Band® and Dr. Jack Yu, director of the Medical College of Georgia Craniofacial Center in Augusta, believe the band will redirect growth and stimulate more bone formation in the front of the skull. That growth could be used in surgery for bone grafts for the back of Samantha's head.

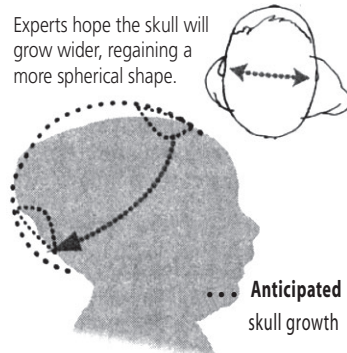


A piece of bone missing from Samantha's skull, the result of encephalocele, creates a soft, penetrable area.



The top of the headband is open, allowing the head to stay cool.

Cranial headbands work by applying a holding pressure to the back and front of the skull, encouraging growth into other areas.



Experts hope the skull will grow wider, regaining a more spherical shape.

If the skull does not fuse, Dr. Yu anticipates bone grafts from the front of the head will be used for the back of the skull.

'Angels' provide free medical flights

By Anne Hart

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Angel Flight pilots are increasingly helping families such as the Allgires as helmets become a more common way to reshape babies' heads. Many tiny patients must make weekly or biweekly trips to have their fittings checked.

"These kids really have to go a lot and for just a short visit usually in and out on the same day," said Savannah pilot Ralph Tolman.

Tolman, like hundreds of members of Angel Flight of Georgia, volunteers his time, his single-engine Mooney and his energy to fly patients and families to and from treatment centers.

"To be a good pilot, you have to fly regularly," Tolman said. "I would much rather do this than just poke holes in clouds. This is a satisfying way of being efficient and helping someone else out."

Angel Flight of Georgia was started in 1983 as a way to provide free air trips for patients who are financially strapped or unable to travel on public transportation.

The goal is that no one be denied potentially life-saving treatment simply because they can't afford the travel costs. Pilots bear the cost of the flight, which can range from \$100 to \$600, Tolman said. Most airports waive the landing fees and give Angel Flight pilots a break on fuel.

Children are the majority of the patients, including ones who need organ transplants and only have a short period of time to get to a hospital. Patients must be ambulatory and able to fit in a small single-engine or twin-engine plane. Medical services are not provided in flight.

Patti Jarriel of Savannah and her 13-year-old son Adam have flown via Angel Flight to Atlanta a few times. Adam has cerebral palsy and recently had hip replacement surgery at Scottish Rite Children's Medical Center.

"They pull off miracles," Jarriel said. "I their slogan says they are earning their halos, but if you ask me, they already have them."

In Savannah, Angel Flights fly in and out of Signature Flight Support Fixed Base Operation at the old terminal at Savannah/Hilton Head International Airport. There's even free popcorn, coffee and iced tea for passengers.

But those are just minor perks compared with the huge convenience of the flights themselves, Jarriel said.

"I don't have an automobile, I don't have any other way of getting him there," she said. "I don't know what I would do without them."

Volunteers often do more than fly patients to treatment.

When they can, they borrow a crew car from the airport and drive patients to treatment centers.

Pilots also coordinate with other Angel Flight branches across the country to transport patients to more distant destinations. Recently, Angel Flights, including the Georgia branch, coordinated a two or three plane relay to fly a patient from Beaufort, S.C. to Canada.



ANGEL FLIGHT OF GEORGIA

• ITS HISTORY

Since 1983 Angel Flight of Georgia, a group of pilot and non-pilot volunteers, fly patients free to and from treatment centers in Georgia, Alabama, Tennessee, Florida, Mississippi and the Carolinas. The nonprofit group works with an independent network of volunteer pilot organizations to ensure travel across the United States.

From 1990-1993, operating on a part-time basis, Angel Flight of Georgia coordinated about one mission per week.

In June 1993, Angel Flight began operations full-time and increased its mission to two per week. The increase continued through 1999, maintaining an annual average of more 200 flights.

Last year, the group made 1,053 flights. So far this year, they've made 445 already.

• TO REQUEST AN ANGEL FLIGHT

Call 1-877-4 AN ANGEL
(877-426-2643)

Photos by John Carrington/Savannah Morning News

Dave Allgire feeds baby daughter Samatha on board the private plane of Statesboro dentist and Angel Flight pilot Richard Marz prior to takeoff on a flight to Atlanta for a doctor's appointment. The Angel Flight program provides free flights on private planes for patients who require specialized medical treatment not available in their area.