



# AGAST

Fourth Quarter 2002

Alliance of Grandparents A Support in Tragedy

www.agast.org

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## AGAST

The Alliance of Grandparents A Support in Tragedy (AGAST) Newsletter is published several times each year. Signed submissions and comments are welcome and should be forwarded to the Coordinator or Editor listed below.

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## Device Detects Fetal Brain Response

### NEW DEVICE DETECTS FETAL BRAIN RESPONSE TO LIGHT

#### May Help Prevent Brain Damage

For years, doctors who work in maternal and fetal medicine have had no way to detect brain activity in unborn children. Now, for the first time, researchers using a unique scanning device have shown that they can detect fetal brain activity in response to flashes of light transmitted through the mother's abdomen. With refinement, this technique may help physicians detect and prevent fetal brain damage resulting from maternal hypertension, diabetes, and other conditions. The work was supported by the National Institute of Neurological Disorders and Stroke (NINDS) and appears in the September 7, 2002, issue of "The Lancet." (1)

The study is one of the first tests of a new device designed to study maternal and fetal physiology, including fetal brain activity, using magnetoencephalography (MEG) of the womb. It also is the first MEG study to use light, rather than pulses of sound, to stimulate the fetus.

"Though this work is preliminary, it is a promising indication of how MEG may help researchers understand the fetal brain," says Giovanna Spinella, M.D., a pediatric neurologist at NINDS.

The new device, called SARA, was conceptualized by Curtis L. Lowery, M.D., of the University of Arkansas for Medical Sciences and developed by CTF Systems Inc., of Port Coquitlam, British Columbia, Canada. NINDS helped to fund development of the device, which is the

first of its kind in the world. SARA stands for SQUID Array for Reproductive Assessment. SQUID is an acronym for Superconducting Quantum Interference Device, a method developed to detect tiny fluctuations in magnetic fields using a superconductor cooled by liquid helium.

Previous studies have shown that maternal hypertension, diabetes, pregnancy with two or more babies at once, and many other conditions can lead to hypoxia (lack of oxygen) that can damage the fetal brain. Prenatal infections, smoking, and other problems also can interfere with normal brain development. Structural problems in the fetal brain can often be detected using magnetic resonance imaging (MRI). However, until recently it has been impossible to directly assess brain activity in an unborn child. Researchers have now begun to experiment with MEG and another type of brain scan, called functional MRI, in order to overcome this problem. Both techniques work by measuring tiny magnetic field changes that result from brain activity.

"To develop therapies, you need to be confident in intrauterine diagnosis," says Dr. Lowery, who led the study. Currently available tests, such as fetal heart-rate monitors, have a high false positive rate, meaning that they often indicate a problem when there really isn't one. Using SARA could help to determine if a baby is really at risk, enabling doctors to better decide when treatments will be beneficial, Dr. Lowery says. Doctors might be able to prevent brain damage by delivering the baby before term, by

(Continued on page 2)

*With refinement, this technique may help physicians detect and prevent fetal brain damage resulting from maternal hypertension, diabetes, and other conditions.*



*The device can also detect the fetal heartbeat, uterine activity, and other physiological factors that may influence a healthy pregnancy outcome...*

## *Device Detects Fetal Brain Response (continued)*

*(Continued from page 1)*

cooling the baby's head after delivery, or someday even by using neuroprotective drugs, he adds.

In the study, Dr. Lowery and his colleagues tested SARA with 10 fetuses that had a gestational age of 28 - 36 weeks and no known risk factors for brain damage. Fetuses whose eyes were more than 3 centimeters from the maternal skin or whose heads were facing down or away from the mother's abdomen were excluded from the study. The expectant mothers sat upright on the SARA machine and leaned forward into a concave array of 151 sensors that surrounded the abdomen. The researchers then used a fiber-optic cable to deliver light pulses to the outside of the mother's abdomen while they recorded MEG data. The light used was about 11 times less intense than sunlight on a bright day.

When they screened out signals from the maternal and fetal heart beats, the researchers found that 4 of the 10 fetuses had measurable brain responses to the light pulses. The time between the light pulses and each fetus's response decreased with increasing gestational age. It is unclear why 6 of the fetuses did not respond to the stimulus, Dr. Lowery says. They may have been asleep during the test, or the position of their heads may have prevented them from seeing the light. He believes researchers may get better results if they test the same fetus re-

peatedly.

Much more testing is needed to define what types of responses indicate normal and abnormal brain activity in fetuses at different gestational ages, Dr. Lowery says. Unborn babies with specific kinds of brain damage may have no response to certain types of stimuli, or a delayed response. The researchers now plan to test larger numbers of fetuses to determine what types of brain responses may indicate a problem. They also plan to test babies born with abnormalities to try to determine how their responses differ from those of other babies. A special "cradle" adapter allows the researchers to scan newborn babies using SARA.

While this study showed that visual stimulation can activate the fetal brain, other types of stimulation may also be used with SARA. These might include auditory stimulation (such as pulses of sound or exposure to a mother's voice), vibration, or magnetic stimulation. Using several different kinds of stimuli may yield more conclusive results than a single test, because different types of stimuli activate different parts of the brain, Dr. Lowery says. The researchers also are investigating whether SARA can detect baseline brain activity in the fetus when no special stimulus is present.

In addition to improving clinical care, SARA may be useful as a research tool to investigate brain development in the womb. Data from such tests

might ultimately lead to new insights about the causes of cerebral palsy and other developmental disorders, and to ways of preventing those disorders. SARA could be used with a visual stimulus as early as the 24th week of pregnancy, when the eyes have matured and the cortex is fully connected to the lower brain regions, according to Dr. Lowery.

The researchers are now planning to develop and test better light stimulators, such as lasers, and to perform serial brain scans, in which they examine a fetus's responses over a period of time. Since SARA also can detect the fetal heartbeat, uterine activity, and other physiological factors that may influence a healthy pregnancy outcome, it ultimately could be used in a variety of clinical tests, the researchers say.

The NINDS is a component of the National Institutes of Health in Bethesda, Maryland, and is the nation's primary supporter of biomedical research on the brain and nervous system.

This release will be posted on EurekaAlert! at [www.eurekaalert.org](http://www.eurekaalert.org) and on the NINDS website at [www.ninds.nih.gov/news](http://www.ninds.nih.gov/news).

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Eswaran H, Wilson JD, Preissl H, Robinson SE, Vrba J, Murphy P, Rose DF, Lowery CL: "Magnetoencephalographic recordings of visual evoked brain activity in the human fetus." 'The Lancet', Vol. 360, No. 9335, pp. 779-780.

## From the Editor's Desk

Sandra and I have returned from the International AIDS Conference in Florence, Italy, and the newsletter has succumbed to my jet lag. Please forgive it for being a tad late.

I wanted to share with you some of my experiences in Italy, but I find that I am still so overwhelmed by the magnificence, the beauty, and the antiquity of the places we visited that I cannot justify putting "pen to paper." I could tell you where we went, what we did, and what we saw, but I am unable to convey what is in my heart — how it **feels** to stand in the middle of the Roman Forum and try to fathom the concept of a city almost 2,700 years old; to walk past a cathedral in Florence that was **reassembled** in the 14<sup>th</sup> century; to turn a corner in Galleria dell'Accademia and look down a hallway at Michaelangelo's David, to walk along that corridor and look up, up, ever upward at the perfection of that chunk of marble, to see the way his left foot seems to grip the pedestal on which he has stood for almost 500 years, the detail of the veins standing out in his hands, the shining beauty of his youthful face, to actually wonder what he is **thinking** as he stands there in his naked splendor.

[I have heard that someone once asked Michaelangelo how he was able to carve such a beautiful statue out of a piece of marble and he replied, "It was easy — I just took my chisel and cut off everything that didn't look like a man." I have been unable to verify the truth of that quote.]

The four of us (Sandy, my two sisters, and I) shared an apartment in Florence



be considered "roomy" if you were an underweight eight-year-old. Once the water (tepid at best, icy at worst) was turned on the curtain swirled inward so that the experience was more a boxing match than a bath. The sleeper sofa was so bad that one of my sisters slept in a chair all week (though the bed Sandy and I shared was **very** comfortable). Between the upstairs tenants and the ristorante next door, the noise lasted into the wee hours. And I never slept better in my life!

The "bambino" upstairs (better known by my sisters as a "granny-magnet") would come out onto his balcony and talk to us as we relaxed in our private garden. When his mother would take him in he would blow us kisses, wave, and say "derci!"

Around the corner was a delightful trattoria where our hostess, Michaela, served us sandwiches, pastries and wine (at very reasonable prices) and her fox terrier, Theresa (pronounced "Tuh-RAY-za"), kept us company while we ate. When we finished eating Michaela

for the week of the conference. There was no air conditioning (and it was **hot**), and some of the "amenities" left somewhat to be desired. There was a front-loading washer in the bathroom, and when it "finished" I opened the door and water gushed everywhere! The shower (no tub), described in the brochure as "roomy," was a curtain around a faucet, and could, by exaggeration,

would call a taxi for us and off we would go to the Uffizi, or the Duomo, or Ponte Vecchio to continue our adventures.

In all those adventures we never lost sight of why we were there — our precious angels. We lit candles for all who requested them (24 in all). We were unable to do so in St. Peter's Basilica (the best I could understand, it was because it was late in the day and there were no candles left), but our wonderful guide, William, went to the Swiss Guards and explained why it was important for us to light candles, and they graciously granted permission for us to enter their church (St. Anne's, I think), which is within the Vatican City but not open to the public.

We also lit candles in Chiesa di S. Michele when we visited the city of Lucca, and we released balloons at the conference memorial service on Sunday night.

We really did manage to attend the conference, as well as make a presentation for AGAST. During one of the family sessions we were privileged to see a re-creation of a Maori mourning ritual, which begins with a "Spirit Leaving Ceremony" and ends with the unveiling of a memorial after a year, "allowing the family to once more publicly share their sorrow, while at the same time releasing them from all future obligations to the deceased, other than quiet remembrance." This ceremony concludes with a feast of thanksgiving.

On our last morning, as we were getting into the van to go to the airport, we saw a huge, complete, rainbow in the eastern sky, stretching from north to south — all our little grandchildren bidding us bon viaggio!

I hope to post our pictures on the website soon — watch for them.

## Upcoming Events

**Plans are underway for this year's National SIDS Alliance conference**, which will be held at the Wyndham Orlando Resort in Orlando, Florida November 15 – 17. There will be Affiliate Development Pre-Conference Workshops November 13-14 and Professional Training Workshops (PHN, First Responder, Peer Contact and Childcare Provider) November 14

### Lodging

A limited block of rooms have been reserved for conference participants at discounted rates. Regular room rates are \$99.00 per night; family and business suites are available for an additional \$30.00 per night.

Family Fun Suites consist of two double beds and a separate room with bunk beds!

The current hotel tax rate is 11%. All rooms are subject to a 7% resort tariff fee, which includes 24 hour health club access, no charge for local telephone calls, waived 800 number access, USA Today delivered daily, pool, concierge services, use of in-room safe, and complimentary in-room coffee and tea.

Book early by calling 1-800-421-8001. Please reference the SIDS Alliance Conference

### Airfare

We are pleased to announce several airline partners for this year's conference:

Through special arrangements with ResourceOne, we have obtained preferential airfare and car rental rates from a variety of companies. Before making reservations or purchasing more expensive, more restrictive or non-refundable tickets through other sources, we suggest you log on to their

web site and submit a reservation quotation request. ResourceOne assures us that you will find these special fares to be lower than published fares. In those few cases where published promotional fares are lower than the preferential fares provided, the lower published fares will be offered.

Since the quantity of seats that are available at the levels negotiated are capacity controlled, ResourceOne suggests that you make reservations as early as possible. As usual, those who make their reservations earliest will obtain the best fares. Ticketing may be delayed to within three weeks prior to departure; however, ticketing within three weeks prior may result in additional charges for express mailing and last minute handling. No reservations will be accepted within 10 days prior to departure, except for published fares.

To submit a reservation quotation, please log on to [www.resourceoneair.com](http://www.resourceoneair.com) and enter the password SIDS2002 and click on the "Login" box. For further information or questions, please call the toll free number, 1-888-682-0138.

#### \*Southwest Air

- 800-433-5368 - Code J6447 (reference National SIDS Alliance)
- Offer valid for travel 11/9 - 11/17
- 10% discount for reservations made at least 5 days prior to travel
- Not valid for one-way travel
- Changes made after purchase must be made at a ticket counter

#### \*US Airways:

- 877-847-7687 - Code 97192425 (reference National SIDS Alliance)
- Offer valid for travel 11/9 - 11/20
- First Class and Lowest Published

#### Fare:

- 5% off following all rules/restrictions
- 10% off with 60 day advance ticketing (all other rules apply)
- Unrestricted 'Y' published fares:
  - 10% off with NO advance ticketing required
  - 15% off with 60 day advance ticketing
- On-Line Reservations Meeting ID #MTG000807
  - Requires registration as a US Airways On-Line Customer

\*Offer not valid in connection with any other discounts

**Yesterday, Today, Tomorrow** — California SIDS Program, October 10<sup>th</sup> and 11<sup>th</sup>, Indian Wells Resort Hotel; 76-661 Hwy 111; Indian Wells, CA, (800) 248-3220. On Friday, October 11<sup>th</sup> Darcie Sims and her daughter Alicia Sims Franklin will hold an all-day grief seminar. For more information call (800) 369-7436 (outside California) or (916) 266-7436 (in California), or e-mail [info@californiasids.com](mailto:info@californiasids.com).

**Don't forget National Children's Memorial Day**, the second Sunday in December (the 8<sup>th</sup> this year). All around the world parents and grandparents light candles at 7:00 p.m., for 24 hours of remembrance around the globe. If there is not an organized ceremony in your area, why not organize one?

*"It isn't for the moment you are struck that you need courage, but for the long uphill climb back to sanity and faith and security."*

Anne Morrow Lindbergh,  
1906 – 2001