

# voices

for August 2009

a newsletter from Sophie's Voice Foundation



## Sophie's Voice goes to Washington

Sophie's Voice Foundation was invited to Washington, D.C. on August 10 to meet with several offices of the Obama Administration, including Health Reform, the Secretary of Health and Human Services, Public Liaison, Secretary of Commerce and the CDC.

SVF's purpose was to advocate for children and adults with spina bifida and to seek a \$200 million annual budget allocation to be given to CDC, beginning with the 2011 budget, for worldwide birth defects initiatives and programs.



Left to right: Ghana Fashion Weekend Director Ibrahim Sima, Nicole, Ghana Vice President John Mahama, Blakofe, Boris and Kiernen Marc

## Fundraising efforts for the *Xiao Procedure* at Children's Healthcare of Atlanta continue

This spring, a major fundraising campaign was launched by Sophie's Voice Foundation to underwrite a \$1.88 million surgical trial of the *Xiao Procedure*.

The medical research project will take place at Children's Healthcare of Atlanta at Scottish Rite Hospital. 21 Physicians from 9 different medical specialties will participate in the surgical trial.

Several small events have been held and individual donations have been received at a steady pace. The first major fundraising event will take place on September 14 in New York City.

## Sophie's Voice opens a chapter in Ghana, Africa and will establish a spina bifida clinic for children and adults

In early July, Boris Kodjoe, Nicole Ari Parker and Jim Okula traveled to Ghana, Africa for the purpose of chartering a chapter of Sophie's Voice Foundation.

The chapter will be known as **Sophie's Voice Ghana** and will be based in the capital city of Accra. Necessary paperwork for recognition as an "NGO" will be filed within the next few months, allowing the organization will be operational by year-end. Ofie Ofuatye-Kodjoe will serve as Executive Director of Sophie's Voice Ghana.

While in Ghana, the SVF team met with the members of the government, including Ghana Vice President John Mahama, Ghana Minister of Health Dr. George Sipa-Adja Yankey and Deputy Minister of Health Dr. Benjamin Kunbuor and received their commitment and support to establish a clinic for children and adults with spina bifida living in Ghana.

The Centers for Disease Control, and Prevention has offered help to initiate a  
see **Ghana**, continued on page four

## Sophie's Voice in the Media

### CNN International

A worldwide audience of 250 million people viewed a recent edition of **Vital Signs** with Dr. Sanjay Gupta which focused on Sophie's Voice. The 30-minute program was broadcast on CNN International and also edited for CNN's Headline News channel.

The 9-minute segment focused on Boris and Nicole raising a daughter with spina bifida and the upcoming surgical trial of the *Xiao Procedure*.

The program was shown worldwide more than 15 times on both networks and generated emails and donations from 9 countries around the world.

### Wendy Williams Show

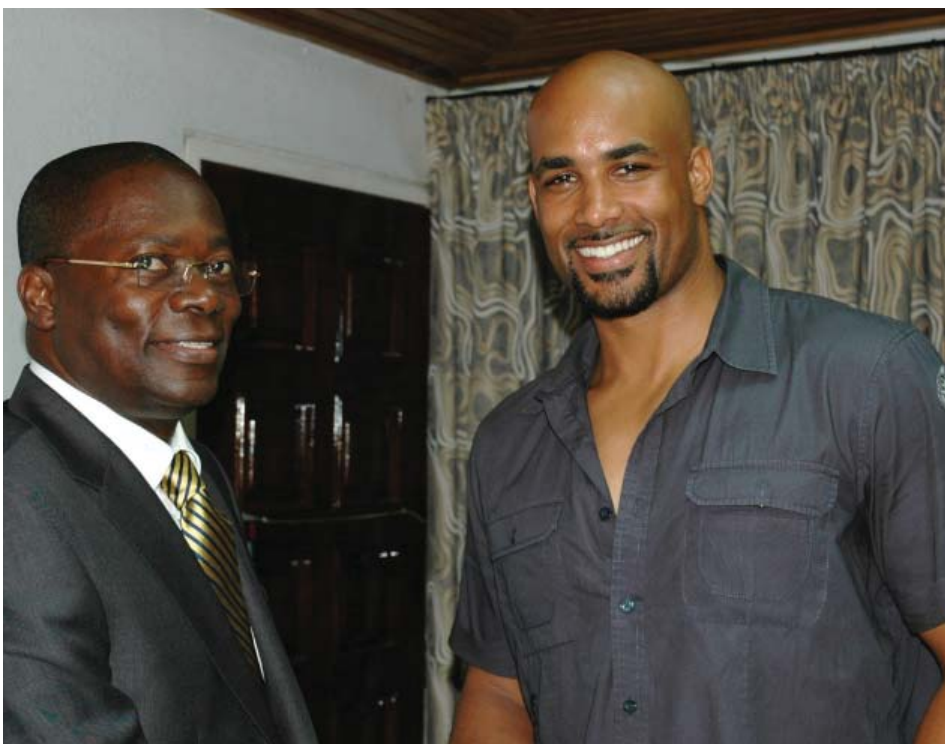
SVF Founder Boris Kodjoe was the opening guest on the Fox-syndicated talk show, the Wendy Williams Show, which aired on July 26.

Kodjoe talked about Sophie's Voice Foundation and its initiatives.

### Usher's Kids Camp

Boris Kodjoe and Nicole Ari Parker were the special guests at Usher's Camp New Look 2009, held at the Alliance Theatre in Atlanta.

The mission of the free, two-week summer camp is to empower children and educate them about the business aspects of sports and entertainment industries.



Ghana Minister of Health Dr. George Sipa-Adja Yankey and Boris Kodjoe meet at the Ghana Ministry of Health offices in Accra



Boris Kodjoe, Ofie Kodjoe, Dr. Kofi Amoah and Nicole Ari Parker at a luncheon hosted by SVF for Ghana business, government and healthcare leaders

## ADD YOUR VOICE TO OURS !

**Together, our voice is stronger as we speak up  
for children and adults with spina bifida -  
all over the world!**

- Join Sophie's Voice Foundation. Go to our website at [www.sophiesvoicefoundation.org](http://www.sophiesvoicefoundation.org) and become a member of SVF
- Donate to Sophie's Voice to support our mission and our initiatives for research, education, prevention and healthcare
- Volunteer for upcoming events in New York City and Atlanta



## Update on the Xiao Procedure

### Preparations for the surgical trial at Children's Healthcare of Atlanta underway

Details for the surgical trial of the *Xiao Procedure* are being finalized so that the research project can begin during 4Q 2009 at Children's Healthcare of Atlanta.

The Spina Bifida Partnership, which is comprised of 21 physicians from Children's Healthcare of Atlanta, Emory University and the Rollins School of Public Health, along with Sophie's Voice Foundation, filed an IRB Application with Children's Healthcare of Atlanta in late 2008 for permission to perform the surgical trial. The application was approved in 2008 and Sophie's Voice accepted the responsibility of raising the necessary \$1.88 million to underwrite the medical research.

Lead investigators for the research will be Dr. Edwin A. Smith, (pediatric urologist) and Dr. William R. Boydston (pediatric neurosurgeon), both of whom see patients in the Spina Bifida Clinic at Scottish Rite Hospital.

With an expectation of beginning the surgeries later this year, preparations for the announcement of the patient enrollment and selection process are underway.

"Because this is a medical research trial, every step of the way is very methodical and meticulous. We have sought and obtained the expertise of many physicians, epidemiologists and researchers. We have designed a plan that meets the highest standards for research, surgery and medical care all managed to exacting guidelines," said Dr. Edwin Smith.

"We are very excited about the real potential which this surgery represents for children with spina bifida."

### Documentary film about Sophie's Voice will premier at Children's Healthcare of Atlanta at Scottish Rite Hospital on August 19

A public screening of a documentary film about Sophie's Voice Foundation will take place in the auditorium at Scottish Rite Hospital on Wednesday, August 19, 2009 at 7:00 pm. The 10-minute documentary was filmed in Atlanta by Birds Nest Productions of New York City.

The film was shot at several locations, including Children's Healthcare of Atlanta at Scottish Rite Hospital, the Rollins School of Public Health at Emory University, the Alpharetta YMCA and the home of SVF Founders Boris Kodjoe and Nicole Ari Parker.

Children and young adults from the Atlanta area, along with their parents, were interviewed for the film, including: Alex Armas and sons, Samuel, Joshua and Zachary; Dr. Michael and Nancy Walker and daughter Sophie; Orfilia Iglesias and son Derek Campos; and Lisa Laarhoven and son Adam.

Physicians from Children's Healthcare, who were interviewed about care for children with spina bifida, include: Dr. Daniel Salinas, Dr. Jay Berkelhamer and Dr. Andrew J. Kirsch. Additionally, Dr. Godfrey P. Oakley, Jr. of the Rollins School of Public Health at Emory University spoke about prevention with folic acid nutrition.

SVF Founders Boris Kodjoe and Nicole Ari Parker will be in attendance for the screening. Refreshments will be served after the screening.

The film also can be viewed online from the Sophie's Voice Foundation website, [www.sophiesvoicefoundation.org](http://www.sophiesvoicefoundation.org).

### SVF Fundraiser planned at the Hearst Tower in New York City for September 14, 2009



A SVF fundraiser to support the surgical trial of the *Xiao Procedure* will be held on September 14, 2009 at the Hearst Tower in New York City.

A leading comedian will be the MC for the invitation only event, which will also include an acoustic performance by a national recording artist. Food for the 250 expected guests will be prepared by an internationally known celebrity chef.

Live auction items will include tennis and golf matches with world-ranked professional athletes and celebrities.

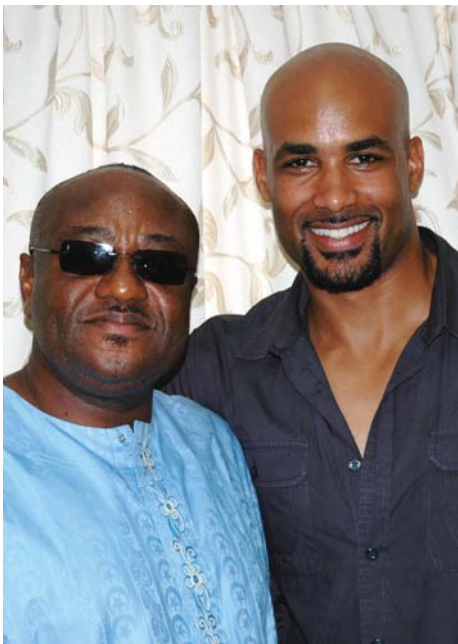
Honorary Chair for the event is Scott M. Sassa of Hearst Entertainment.

Volunteers are needed for the event - contact Jim Okula at 404.502.1314.

## More photos from Ghana, Africa



Nicole Ari Parker and Ghana media personality Blakofe at Cape Coast Castle



Ghana businessman Prosper Adabla and Boris Kodjoe at a luncheon hosted by SVF



Nicole Ari Parker and a vendor at Cape Coast Castle, a historic slave trading center in Ghana

## How you can support Sophie's Voice

As the activities and initiatives of Sophie's Voice Foundation grow and expand, so do the needs for financial support and volunteer efforts. Here are a few ways in which members of the community can lend their support:

(1) Email your friends and associates about SVF and to ask them to make a donation online at the SVF website - [www.sophiesvoicefoundation.org](http://www.sophiesvoicefoundation.org). It's fast, easy and secure - and both major credit cards and checks are accepted. For background information on SVF, send them an electronic copy of this newsletter.

(2) Host a block party. Invite friends

and associates to attend a small party at your home. Handout the donation cards available for download from the SVF website (see "Downloads") and ask them to support your donation with one of their own. For additional information on hosting a block party, contact Jim Okula (*contact information listed below*).

(3) Talk with fellow members of the organizations to which you belong about staging a fundraiser to benefit SVF. Often groups which have annual charitable events are looking for a new organization to be recipient of the funds they raise. Recommend they consider Sophie's Voice Foundation. Remember, our mission includes prevention - each year 60 million women of child-bearing age are at risk of having a baby with spina bifida!

## Ghana *continued from page one*

surveillance project to determine the current population of children and adults living with spina bifida, along with the mortality rate over the past five years.

In addition, Dr. Godfrey P. Oakley, Jr., known worldwide for his efforts to establish folic acid fortification for the prevention of spina bifida, will join SVF in Ghana to setup help convert Ghana flour mills to include fortification with folic acid.

Folic acid has been proven to prevent 70% of spina bifida births when 400 mcgs. are consumed daily for a three months prior to conception and for three months afterwards.

During 4Q 2009, SVF and physicians and healthcare providers affiliated with Children's Healthcare of Atlanta and other medical organizations in the US will travel to Ghana to work with local physicians to establish a spina bifida clinic and host a two-day symposium on healthcare for individuals living with spina bifida.

"Our hope" said SVF Founder Boris Kodjoe "is to establish a model of care in Ghana for those with spina bifida that can become the model for all countries in Africa."

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a newsletter from  
Sophie's Voice Foundation

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