SPINA BIFIDA
ASSOCIATION

Spina Bifida Association Overview

Sara Struwe, MPA

President & CEO

SBA Mission

& Core Programs

Spina Bifida Association Mission

The mission of the Spina Bifida Association is to promote the prevention of Spina Bifida and enhance the lives of all affected.

We work to make a practical, positive difference every day, helping to improve care so individuals can enjoy life to the fullest.

We provide information, resources, assistance, advocacy, and connections to help all those affected by Spina Bifida

SBA Core Programs

- Research
- Clinical Care
- Advocacy
- Education & Support
- Network Building

RESEARCH

SBA, through the Spina Bifida Collaborative Care Network, leads research to enhance the quality of life for people with Spina Bifida.

Research

Conduct
Research

Facilitate
Research

Create
Research Agenda

Conduct Research

Adult Survey

Community Survey

Conduct Research

DME Coverage

AFOs

Facilitate Research

Registry for women with disabilities interested in participating in gynecological and reproductive health research (University of MI)

Patient care perspective on the catheter-using experience and the decision-making process to buy catheters (Northwestern University)

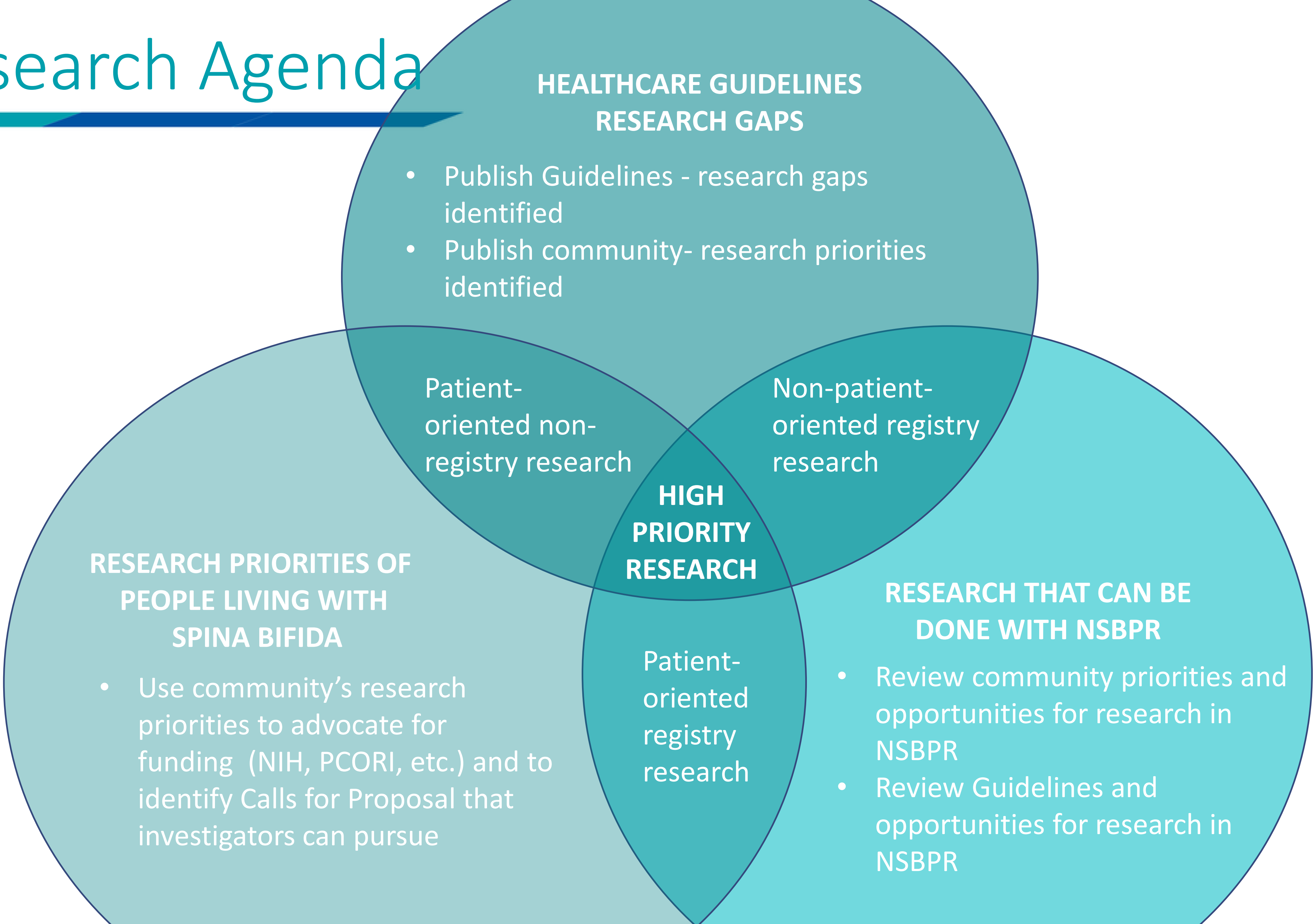
Neonates with Myelomeningocele and Sleep-Disordered Breathing (University of MI)

Body Composition and Energy Expenditure in Youth with Spina Bifida (University of WI Milwaukee)

Survey to learn more about patient and caregiver experiences managing congenital urologic conditions (UCSF)

Sexual health education for people with Spina Bifida and Cerebral Palsy (University of WI Madison)

Research Agenda



HEALTHCARE GUIDELINES RESEARCH GAPS

- Publish Guidelines - research gaps identified
- Publish community- research priorities identified

Patient-oriented non-registry research

Non-patient-oriented registry research

HIGH PRIORITY RESEARCH

RESEARCH PRIORITIES OF PEOPLE LIVING WITH SPINA BIFIDA

- Use community’s research priorities to advocate for funding (NIH, PCORI, etc.) and to identify Calls for Proposal that investigators can pursue

Patient-oriented registry research

RESEARCH THAT CAN BE DONE WITH NSBPR

- Review community priorities and opportunities for research in NSBPR
- Review Guidelines and opportunities for research in NSBPR

CLINICAL CARE

SBA spearheads, through the Spina Bifida Collaborative Care Network, efforts to improve clinical care for all people with Spina Bifida.

Clinical Care Approach

Clinical Care

Clinics/

HCPs

Translational Research

Outcomes

Transition

Adult Care

Partnerships

Clinics/HCPS

SPINA BIFIDA ASSOCIATION & Ann & Robert H. Lurie Children's Hospital of Chicago

present the

Spina Bifida Clinical Care Meeting

Translational Research

GUIDELINES FOR THE
CARE OF PEOPLE WITH
SPINA BIFIDA

SPINA BIFIDA
ASSOCIATION

Outcomes

About the National Spina Bifida Patient Registry

Español (Spanish)

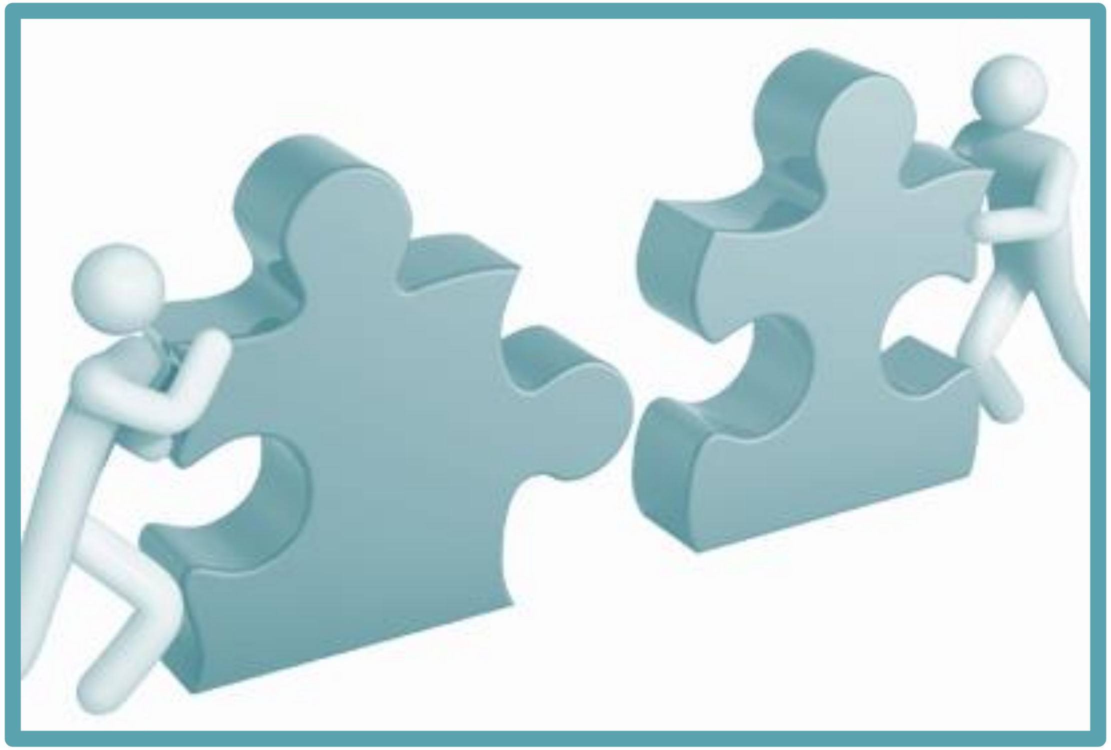
CDC programs and research improve the quality of life and encourage full participation at every age for those with spina bifida. In 2006, a survey of spina bifida clinics across the United States conducted by the Spina Bifida Association (SBA) identified differences in staffing, delivery of services, and patient care. To address these gaps, SBA's Professional Advisory Council advocated for the establishment of the National Spina Bifida Patient Registry (NSBPR) at CDC, to collect the scientific data needed to evaluate existing medical services for spina bifida patients. Established in 2008, the Registry provides the framework for a systematic approach to improving the quality of care received at spina bifida clinics nationwide.

The CDC funds and manages the NSBPR. Progress toward project milestones is monitored, and experts are consulted to ensure the scientific data are useable and valuable to researchers, health care professionals, and families affected by spina bifida.

Findings from the National Spina Bifida Patient Registry

The Centers for Disease Control and Prevention (CDC) reports findings from the National Spina Bifida Patient Registry. The Registry collects information from patients to better understand the associations between medical procedures and health outcomes.

Transition Support



Adult Care

Partnerships

American
Urological
Association

American Academy
of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

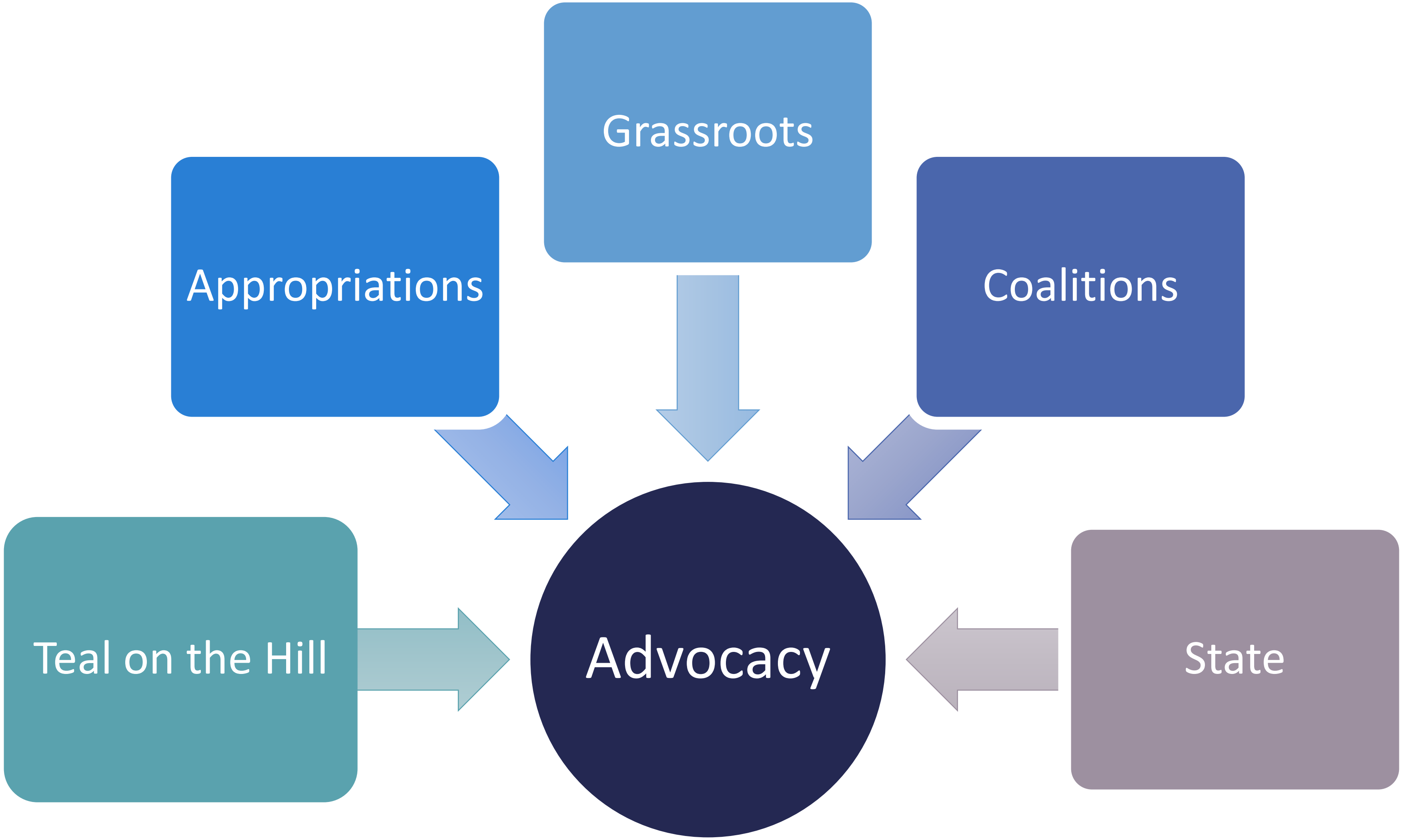
Association *of* Academic Physiatrists

MENTOR. DISCOVER. LEAD.

ADVOCACY

SBA advocates for positive change to the issues impacting the lives of people with Spina Bifida.

Strategies for Advocacy



Grassroots

Appropriations

Coalitions

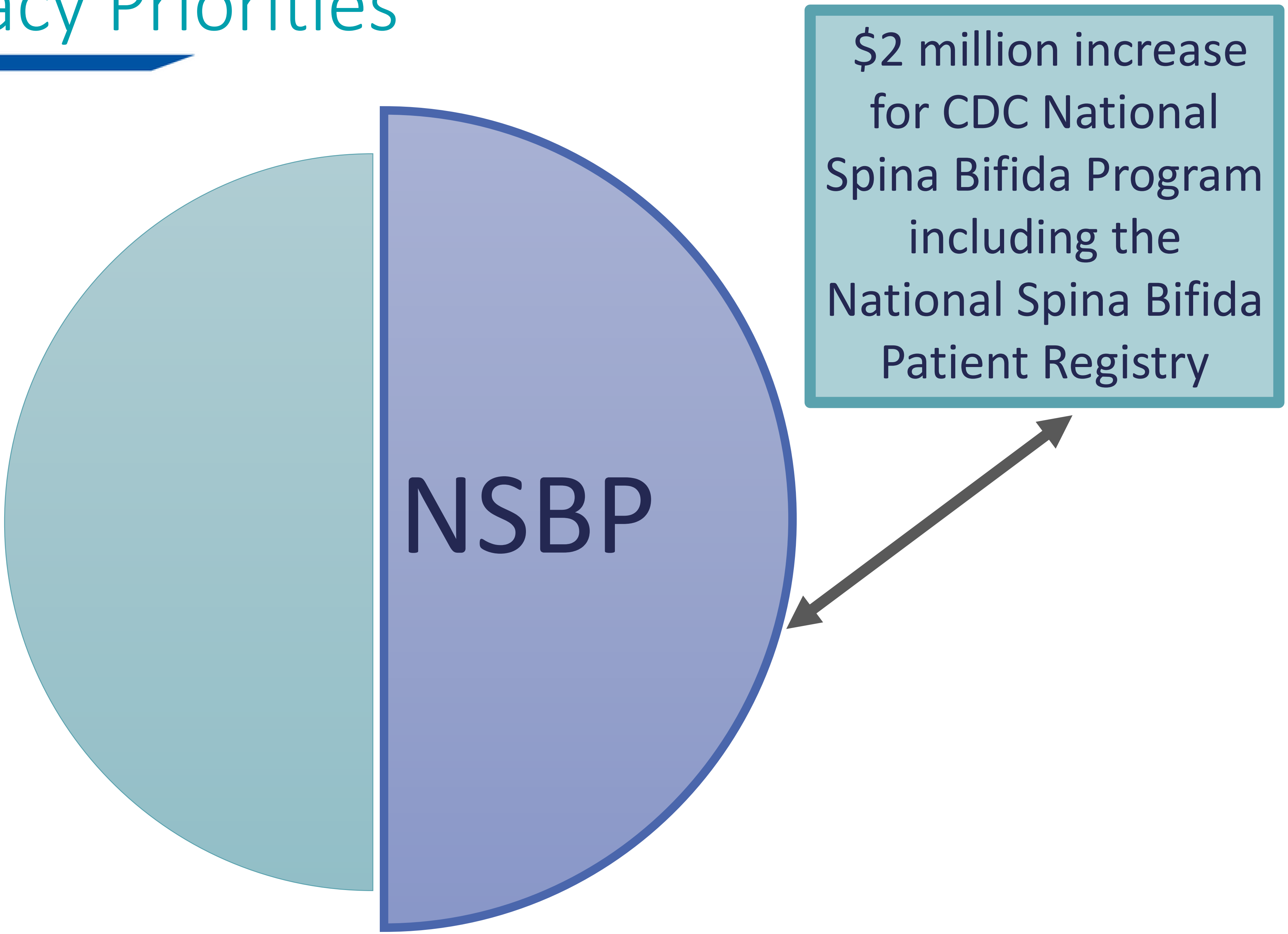
Teal on the Hill

Advocacy

State

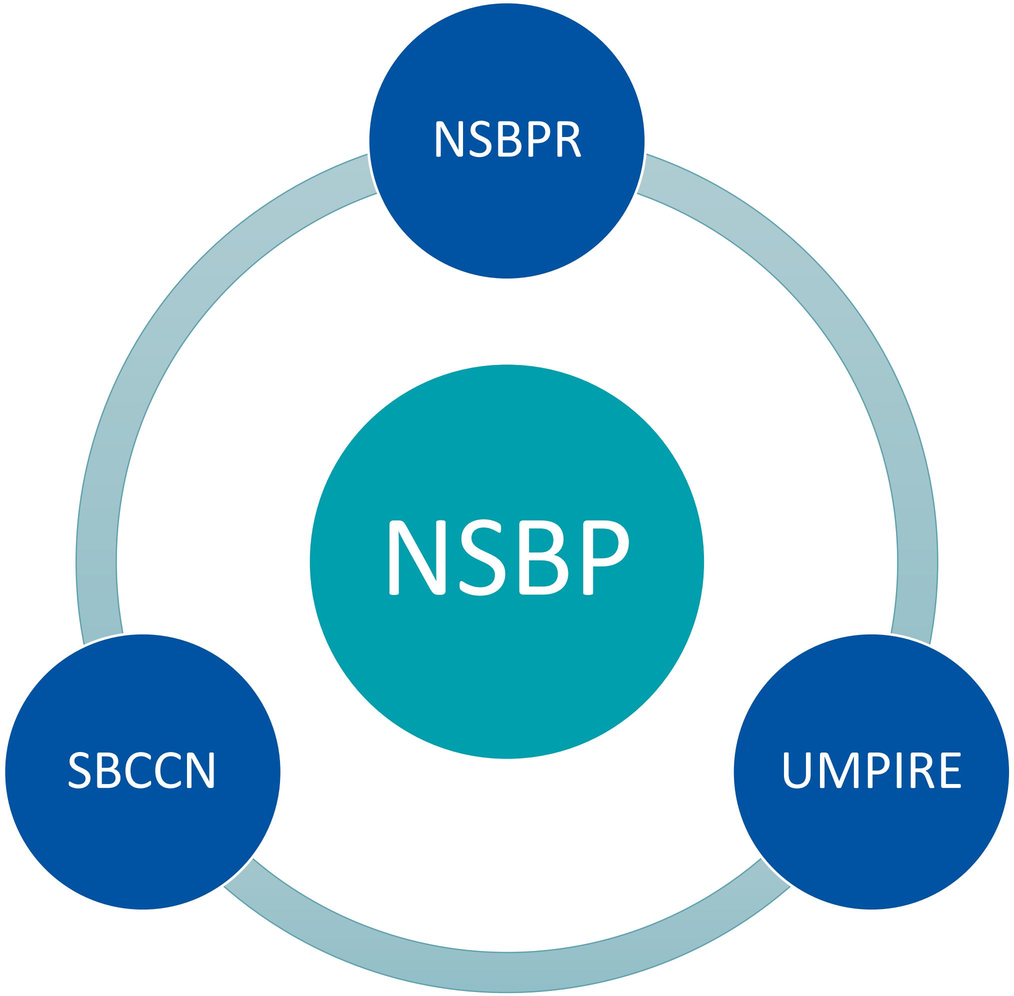
Teal on the Hill

2019 Advocacy Priorities



$2 million increase for CDC National Spina Bifida Program including the National Spina Bifida Patient Registry

Appropriations


NSBPR

NSBP

SBCCN

UMPIRE

CDC Funding Increase Will Aid

Increase clinic participation in NSBPR

Research Barriers to Adult Care

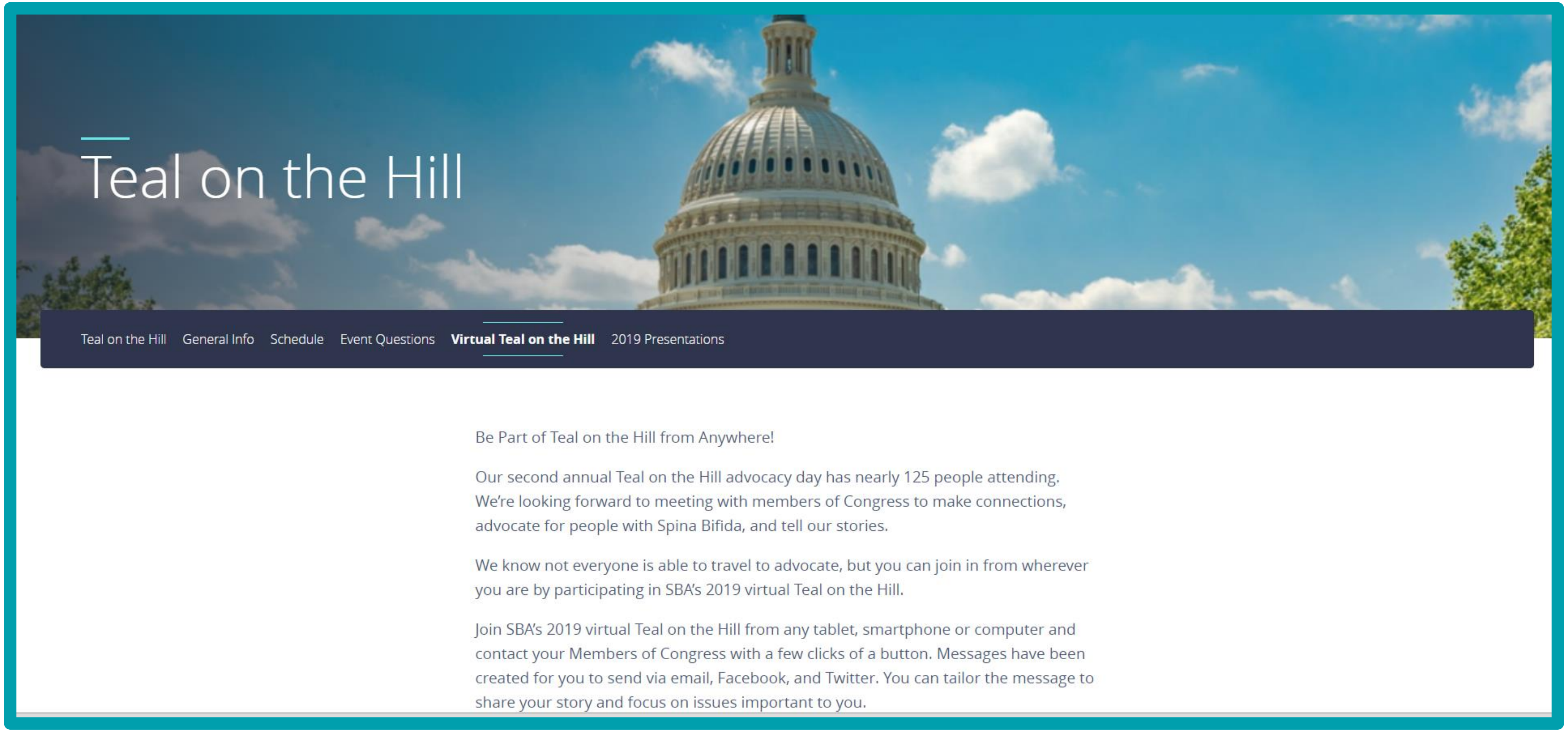
Social Determinants of Health

Hydrocephalus Protocol

Sudden Unexplained Death

# of People with SB

Grassroots



Be Part of Teal on the Hill from Anywhere!

Our second annual Teal on the Hill advocacy day has nearly 125 people attending. We're looking forward to meeting with members of Congress to make connections, advocate for people with Spina Bifida, and tell our stories.

We know not everyone is able to travel to advocate, but you can join in from wherever you are by participating in SBA's 2019 virtual Teal on the Hill.

Join SBA's 2019 virtual Teal on the Hill from any tablet, smartphone or computer and contact your Members of Congress with a few clicks of a button. Messages have been created for you to send via email, Facebook, and Twitter. You can tailor the message to share your story and focus on issues important to you.

Coalitions

- Support other disability legislation
- Support select corporation legislation
- Support other health related legislation

2019 Advocacy Priorities

Protect access for specialized equipment for manual wheelchairs by supporting the House and Senate bills (HR 3730 and S 486 respectively)

Wheelchair

EDUCATION & SUPPORT

SBA Empowers members of the Spina Bifida community with information and support to improve their quality of life.

Education and Support

Education and Support

All of us need someone to care for us. In
the case of individuals with spina bifida,
we need not only family and
close friends, but also
members of the larger
community who
appreciate what every
person has to contribute.
We all benefit from this
kind of compassionate,
inclusive environment.
-Diane Glass

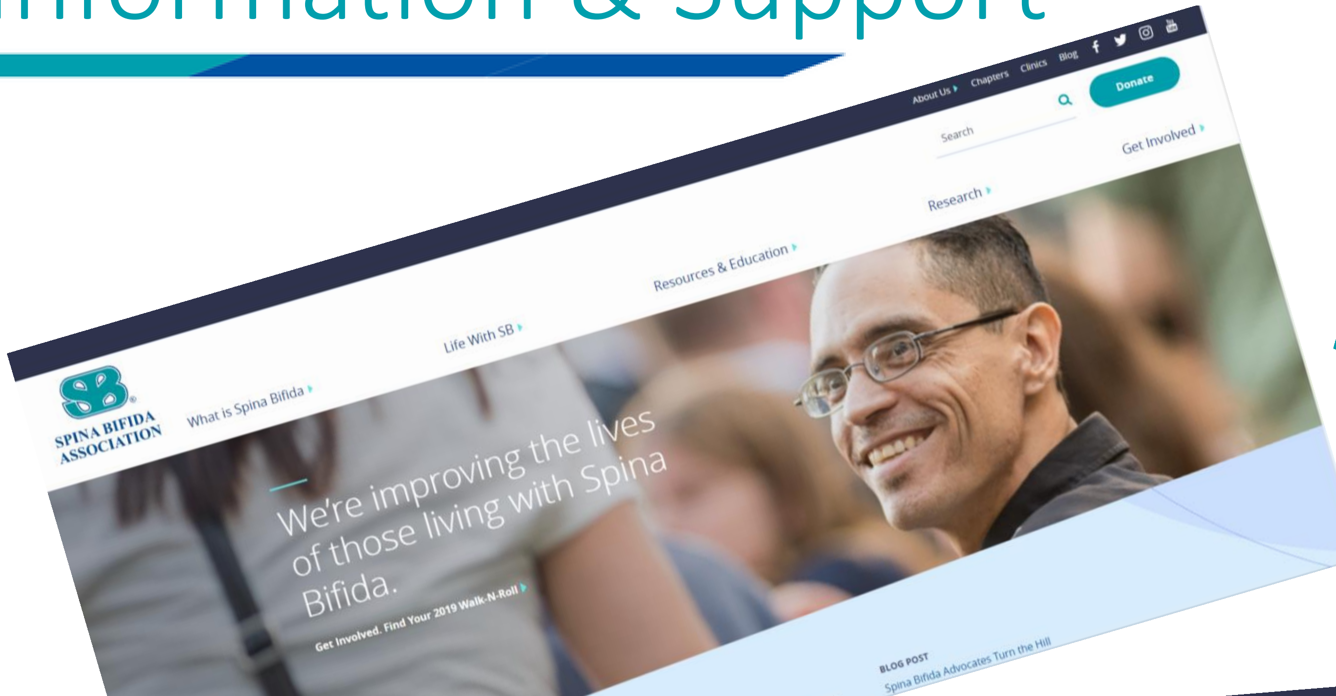
Information & Support

Education

"What people with Spina
need most is care from,
just clinics, but from clinici
who are willing
learn about how we
different and how
treat us to impro
our hea
and quality of li
-Monica

NRC

Information & Support



We're improving the lives of those living with Spina Bifida.

Get Involved. Find Your 2019 Walk-N-Roll

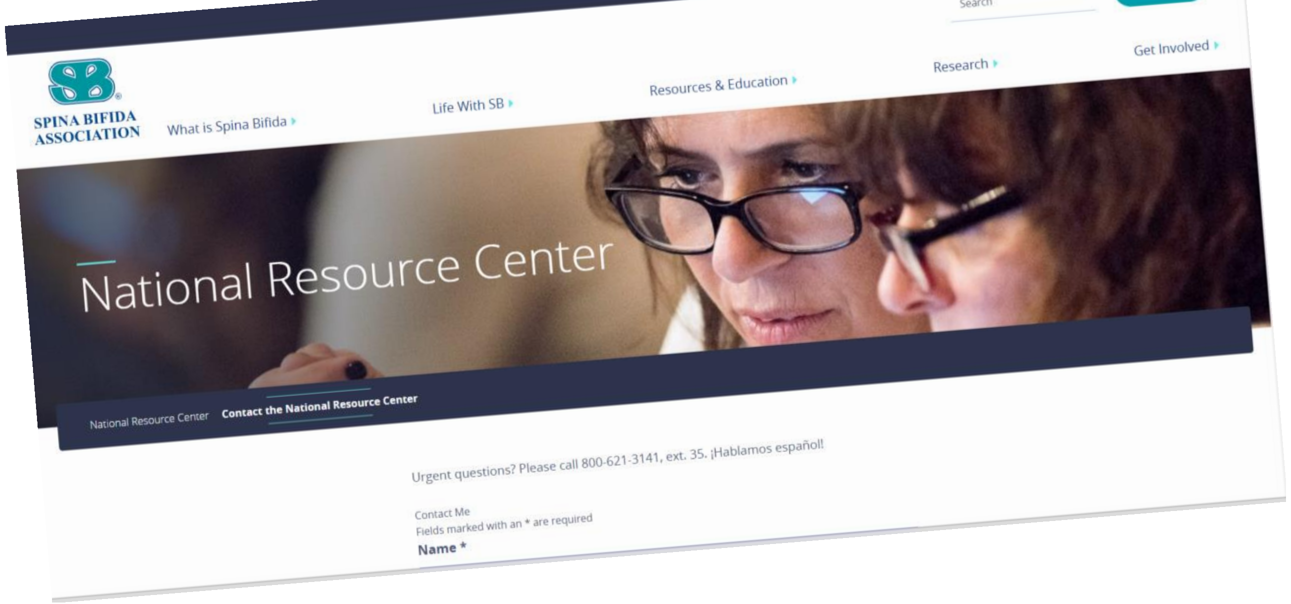
NEWS
House Appropriations Committee

BLOG POST
Teal on The Hill Scholarship Recipient:

BLOG POST
Spina Bifida Advocates Turn the Hill


SPINA BIFIDA ASSOCIATION

OKLAHOMA SB CONNECT



National Resource Center

Urgent questions? Please call 800-621-3141, ext. 35. ¡Hablamos español!

Contact Me
Fields marked with an * are required

Name *

Education Days

June 8, 2019

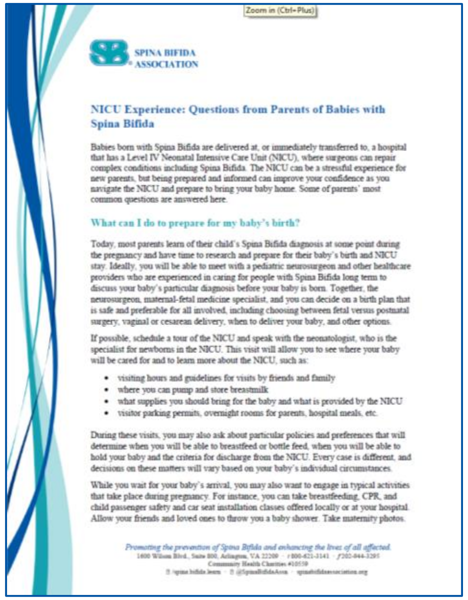
August 3, 2019

September 21, 2019

October 12, 2019

SB-YOU

SB-YOU



SPINA BIFIDA ASSOCIATION

NICU Experience: Questions from Parents of Babies with Spina Bifida

Babies born with Spina Bifida are delivered at, or immediately transferred to, a hospital that has a Level IV Neonatal Intensive Care Unit (NICU), where surgeons can repair complex conditions including Spina Bifida. The NICU can be a stressful experience for new parents, but being prepared and informed can improve your confidence as you navigate the NICU and prepare to bring your baby home. Some of parents' most common questions are answered here.

What can I do to prepare for my baby's birth?

Today, most parents learn of their child's Spina Bifida diagnosis at some point during the pregnancy and have time to research and prepare for their baby's birth and NICU stay. Ideally, you will be able to meet with a pediatric neurosurgeon and other healthcare providers who are experienced in caring for people with Spina Bifida long term to discuss your baby's particular diagnosis before your baby is born. Together, the neurosurgeon, maternal-fetal medicine specialist, and you can decide on a birth plan that is safe and preferable for all involved, including choosing between fetal versus postnatal surgery, vaginal or cesarean delivery, when to deliver your baby, and other options.

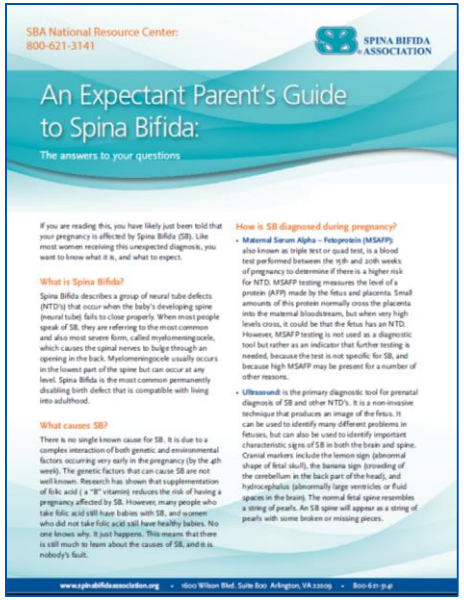
If possible, schedule a tour of the NICU and speak with the neonatologist, who is the specialist for newborns in the NICU. This visit will allow you to see where your baby will be cared for and to learn more about the NICU, such as:

- visiting hours and guidelines for visits by friends and family
- where you can pump and store breastmilk
- what supplies you should bring for the baby and what is provided by the NICU
- visitor parking permits, overnight rooms for parents, hospital meals, etc.

During these visits, you may also ask about particular policies and preferences that will determine when you will be able to breastfeed or bottle feed, when you will be able to hold your baby and the criteria for discharge from the NICU. Every case is different, and decisions on these matters will vary based on your baby's individual circumstances.

While you wait for your baby's arrival, you may also want to engage in typical activities that take place during pregnancy. For instance, you can take breastfeeding, CPR, and child passenger safety and car seat installation classes offered locally or at your hospital. Allow your friends and loved ones to throw you a baby shower. Take maternity photos.

Promoting the prevention of Spina Bifida and enhancing the lives of all affected.
1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · t 800-621-3141 · f 202-944-3295
Community Health Charities #10559



SBA National Resource Center:
800-621-3141

SPINA BIFIDA ASSOCIATION

An Expectant Parent's Guide to Spina Bifida:

The answers to your questions

If you are reading this, you have likely just been told that your pregnancy is affected by Spina Bifida (SB). Like most women receiving this unexpected diagnosis, you want to know what it is, and what to expect.

What is Spina Bifida?

Spina Bifida describes a group of neural tube defects (NTD's) that occur when the baby's developing spine (neural tube) fails to close properly. When most people speak of SB, they are referring to the most common and also most severe form, called myelomeningocele, which causes the spinal nerves to bulge through an opening in the back. Myelomeningocele usually occurs in the lowest part of the spine but can occur at any level. Spina Bifida is the most common permanently disabling birth defect that is compatible with living into adulthood.

What causes SB?

There is no single known cause for SB. It is due to a complex interaction of both genetic and environmental factors occurring very early in the pregnancy (by the 4th week). The genetic factors that can cause SB are not well known. Research has shown that supplementation of folic acid (a "B" vitamin) reduces the risk of having a pregnancy affected by SB. However, many people who take folic acid still have babies with SB, and women who did not take folic acid still have healthy babies. No one knows why. It just happens. This means that there is still much to learn about the causes of SB, and it is nobody's fault.

How is SB diagnosed during pregnancy?

- **Maternal Serum Alpha – Fetoprotein (MSAFP):** also known as triple test or quad test, is a blood test performed between the 15th and 20th weeks of pregnancy to determine if there is a higher risk for NTD. MSAFP testing measures the level of a protein (AFP) made by the fetus and placenta. Small amounts of this protein normally cross the placenta into the maternal bloodstream, but when very high levels cross, it could be that the fetus has an NTD. However, MSAFP testing is not used as a diagnostic tool but rather as an indicator that further testing is needed, because the test is not specific for SB, and because high MSAFP may be present for a number of other reasons.
- **Ultrasound:** is the primary diagnostic tool for prenatal diagnosis of SB and other NTD's. It is a non-invasive technique that produces an image of the fetus. It can be used to identify many different problems in fetuses, but can also be used to identify important characteristic signs of SB in both the brain and spine. Cranial markers include the lemon sign (abnormal shape of fetal skull), the banana sign (crowding of the cerebellum in the back part of the head), and hydrocephalus (abnormally large ventricles or fluid spaces in the brain). The normal fetal spine resembles a string of pearls. An SB spine will appear as a string of pearls with some broken or missing pieces.

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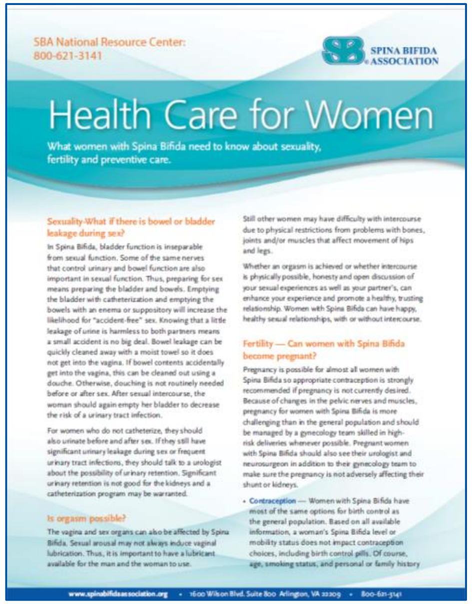

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SPINA BIFIDA ASSOCIATION

Health Care for Women

What women with Spina Bifida need to know about sexuality, fertility and preventive care.

Sexuality-What if there is bowel or bladder leakage during sex?

In Spina Bifida, bladder function is inseparable from sexual function. Some of the same nerves that control urinary and bowel function are also important in sexual function. Thus, preparing for sex means preparing the bladder and bowels. Emptying the bladder with catheterization and emptying the bowels with an enema or suppository will increase the likelihood for "accident-free" sex. Knowing that a little leakage of urine is harmless to both partners means a small accident is no big deal. Bowel leakage can be quickly cleaned away with a moist towel so it does not get into the vagina. If bowel contents accidentally get into the vagina, this can be cleaned out using a douche. Otherwise, douching is not routinely needed before or after sex. After sexual intercourse, the woman should again empty her bladder to decrease the risk of a urinary tract infection.

For women who do not catheterize, they should also urinate before and after sex. If they still have significant urinary leakage during sex or frequent urinary tract infections, they should talk to a urologist about the possibility of urinary retention. Significant urinary retention is not good for the kidneys and a catheterization program may be warranted.

Is orgasm possible?

The vagina and sex organs can also be affected by Spina Bifida. Sexual arousal may not always induce vaginal lubrication. Thus, it is important to have a lubricant available for the man and the woman to use.

Still other women may have difficulty with intercourse due to physical restrictions from problems with bones, joints and/or muscles that affect movement of hips and legs.

Whether an orgasm is achieved or whether intercourse is physically possible, honesty and open discussion of your sexual experiences as well as your partner's, can enhance your experience and promote a healthy, trusting relationship. Women with Spina Bifida can have happy, healthy sexual relationships, with or without intercourse.

Fertility — Can women with Spina Bifida become pregnant?

Pregnancy is possible for almost all women with Spina Bifida so appropriate contraception is strongly recommended if pregnancy is not currently desired. Because of changes in the pelvic nerves and muscles, pregnancy for women with Spina Bifida is more challenging than in the general population and should be managed by a gynecology team skilled in high-risk deliveries whenever possible. Pregnant women with Spina Bifida should also see their urologist and neurosurgeon in addition to their gynecology team to make sure the pregnancy is not adversely affecting their shunt or kidneys.

- **Contraception** — Women with Spina Bifida have most of the same options for birth control as the general population. Based on all available information, a woman's Spina Bifida level or mobility status does not impact contraception choices, including birth control pills. Of course, age, smoking status, and personal or family history

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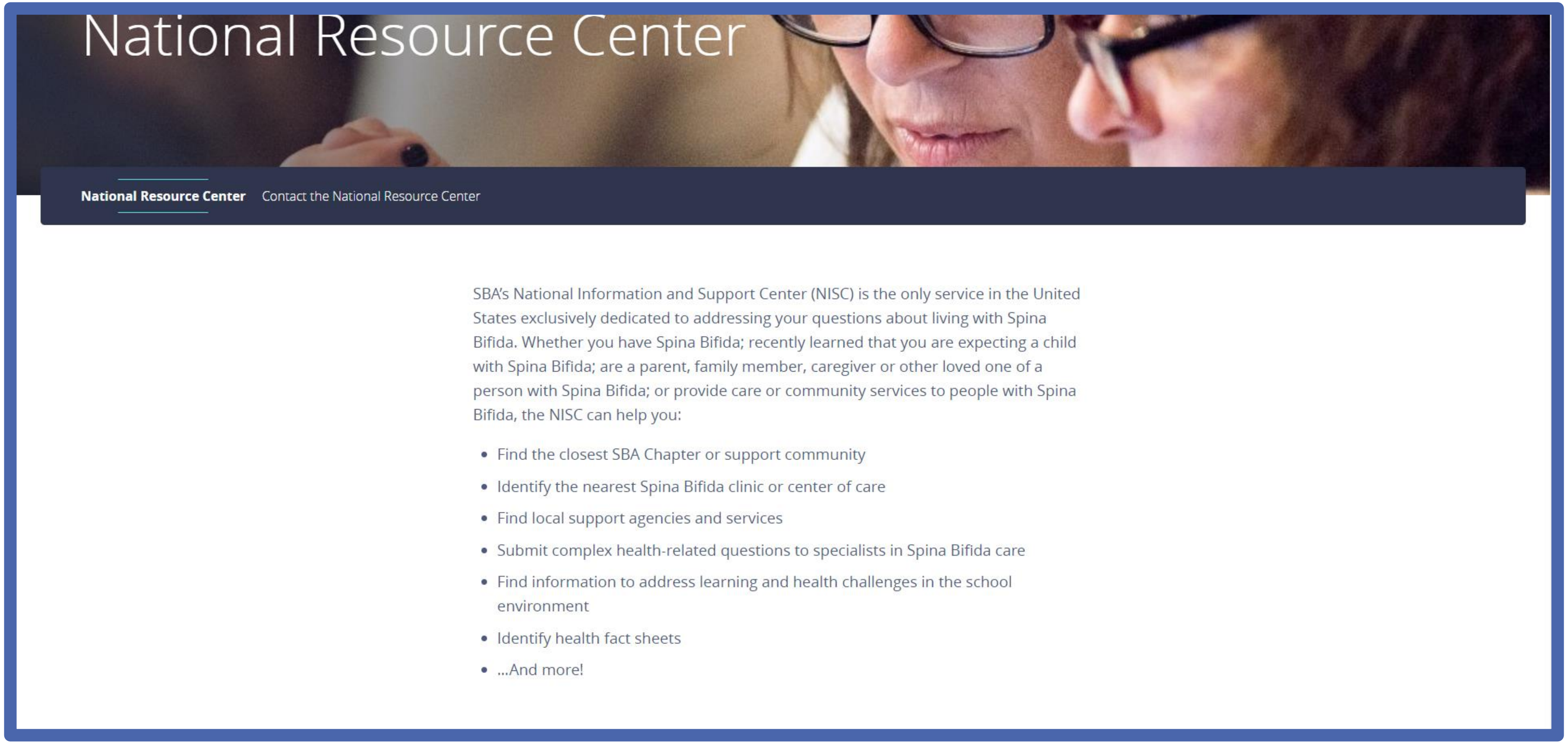
NRC



National Resource Center

SBA's National Information and Support Center (NISC) is the only service in the United States exclusively dedicated to addressing your questions about living with Spina Bifida. Whether you have Spina Bifida; recently learned that you are expecting a child with Spina Bifida; are a parent, family member, caregiver or other loved one of a person with Spina Bifida; or provide care or community services to people with Spina Bifida, the NISC can help you:

- Find the closest SBA Chapter or support community
- Identify the nearest Spina Bifida clinic or center of care
- Find local support agencies and services
- Submit complex health-related questions to specialists in Spina Bifida care
- Find information to address learning and health challenges in the school environment
- Identify health fact sheets
- ...And more!

NETWORK BUILDING

SBA serves as a hub to connect Chapters, clinics, and the broader community to improve the quality of life of people affected by Spina Bifida.

Network Building

Network Building

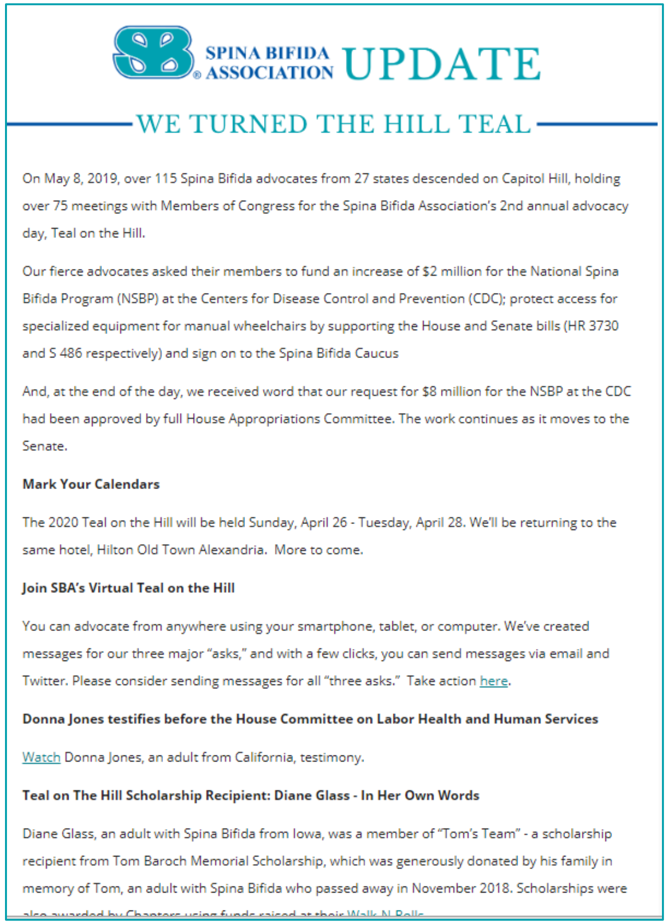
Strengthen SBA Chapters

Strengthen awareness and understanding of SBA activities and resources for all audiences

SBA Chapters

- Alabama
- Arizona
- California
- Carolinas
- Colorado
- Central Florida
- Delaware Valley
- Georgia-Tennessee
- Greater New England
- Intermountain Region
- Indiana
- Iowa
- Kentucky
- Michigan
- Mid-Atlantic Region
- Northeastern New York
- North Texas

Communications



SPINA BIFIDA ASSOCIATION UPDATE

WE TURNED THE HILL TEAL

On May 8, 2019, over 115 Spina Bifida advocates from 27 states descended on Capitol Hill, holding over 75 meetings with Members of Congress for the Spina Bifida Association's 2nd annual advocacy day, Teal on the Hill.

Our fierce advocates asked their members to fund an increase of $2 million for the National Spina Bifida Program (NSBP) at the Centers for Disease Control and Prevention (CDC); protect access for specialized equipment for manual wheelchairs by supporting the House and Senate bills (HR 3730 and S 486 respectively) and sign on to the Spina Bifida Caucus

And, at the end of the day, we received word that our request for $8 million for the NSBP at the CDC had been approved by full House Appropriations Committee. The work continues as it moves to the Senate.

Mark Your Calendars

The 2020 Teal on the Hill will be held Sunday, April 26 - Tuesday, April 28. We'll be returning to the same hotel, Hilton Old Town Alexandria. More to come.

Join SBA's Virtual Teal on the Hill

You can advocate from anywhere using your smartphone, tablet, or computer. We've created messages for our three major "asks," and with a few clicks, you can send messages via email and Twitter. Please consider sending messages for all "three asks." Take action here.

Donna Jones testifies before the House Committee on Labor Health and Human Services

Watch Donna Jones, an adult from California, testimony.

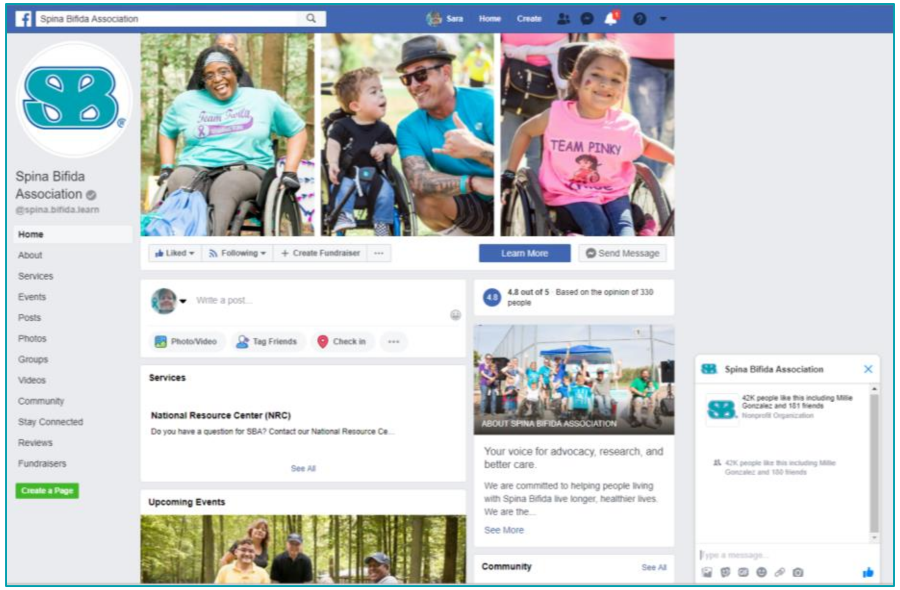
Teal on The Hill Scholarship Recipient: Diane Glass - In Her Own Words

Diane Glass, an adult with Spina Bifida from Iowa, was a member of "Tom's Team" - a scholarship recipient from Tom Baroch Memorial Scholarship, which was generously donated by his family in memory of Tom, an adult with Spina Bifida who passed away in November 2018. Scholarships were also awarded by Chapters using funds raised at their Walk-N-Rolls

BLOG POST | JUN 5, 2019

Spina Bifida Advocates Turn the Hill Teal

On May 8, 2019, over 115 Spina Bifida advocates from 27 states descended on Capitol Hill, holding over 75 meetings with Members of Congress for the Spina Bifida



4.8 out of 5 · Based on the opinion of 330 people

Services

National Resource Center (NRC)

Do you have a question for SBA? Contact our National Resource Ce...

See All

Your voice for advocacy, research, and better care.

We are committed to helping people living with Spina Bifida live longer, healthier lives. We are the...

Spina Bifida Association

42K people like this including Millie Gonzalez and 181 friends

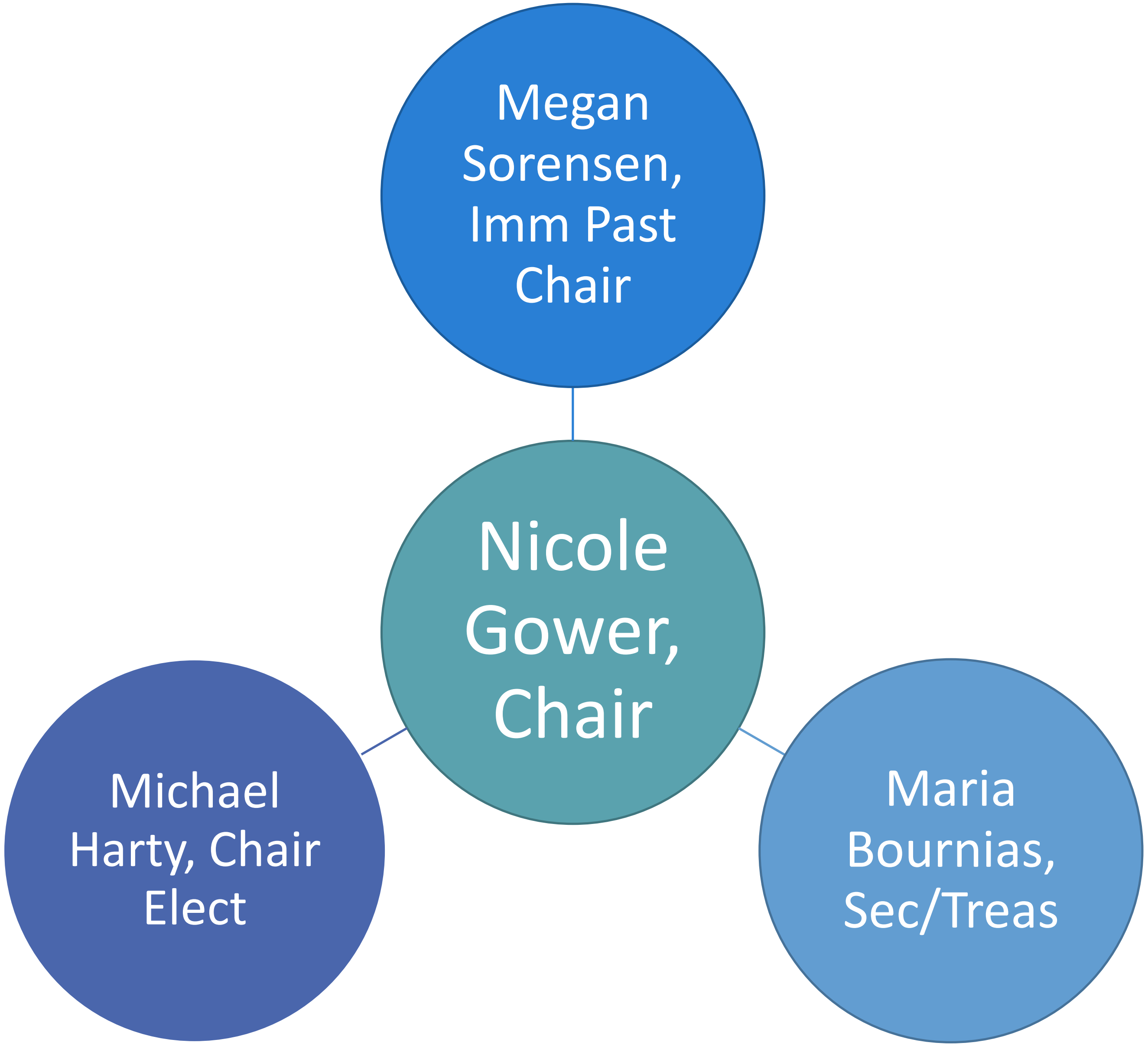
Nonprofit Organization

42K people like this including Millie Gonzalez and 180 friends

Type a message...

PEOPLE

Board Officers



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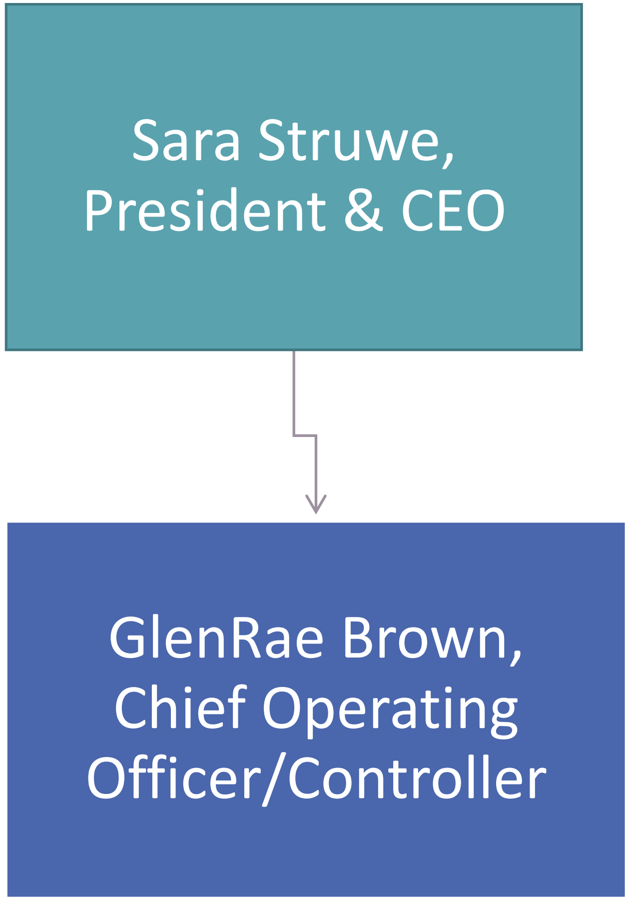
Nicole Gower, Chair

Michael Harty, Chair Elect

Maria Bournias, Sec/Treas



Sara Struwe, President & CEO

GlenRae Brown, Chief Operating Officer/Controller

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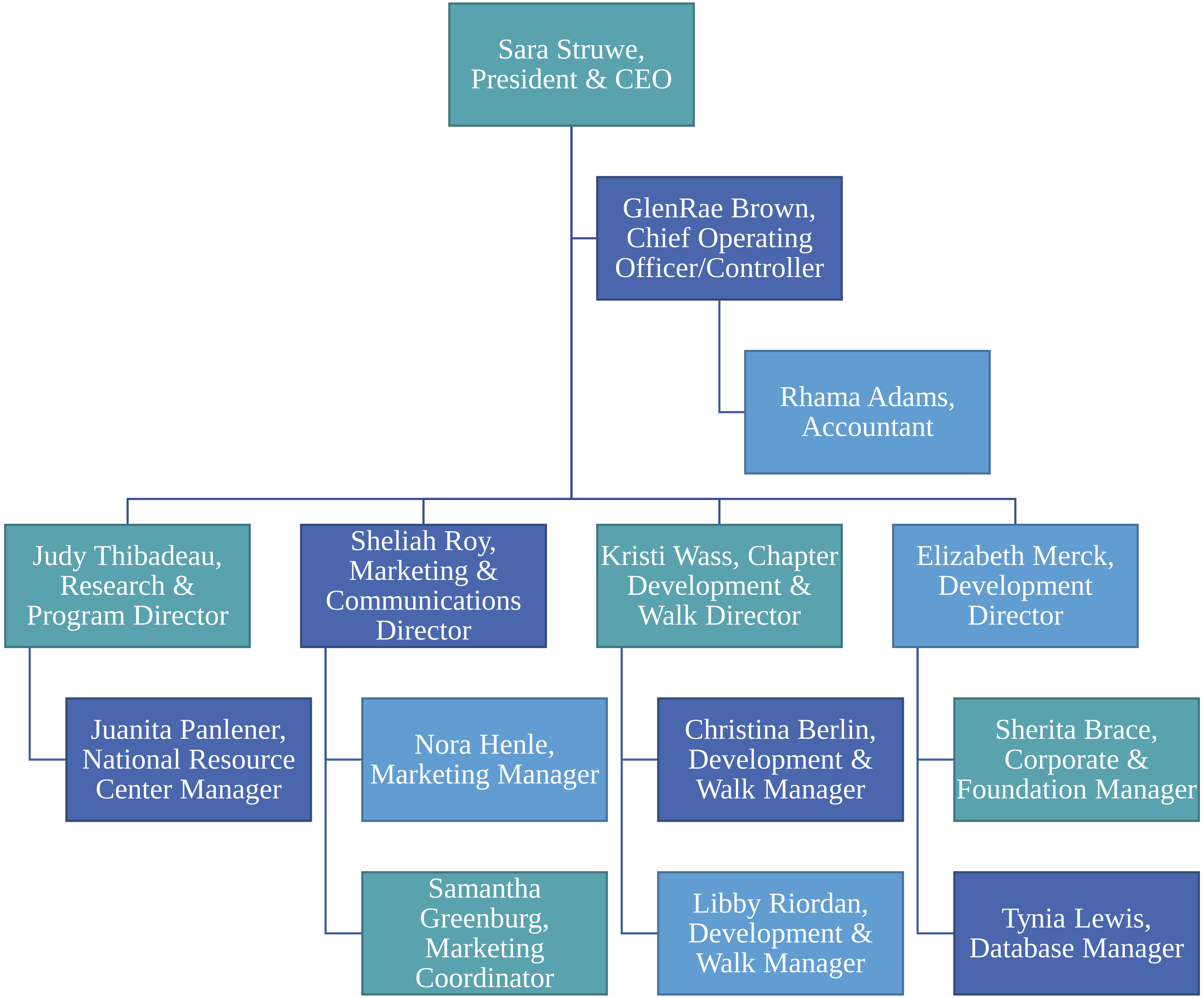

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THANK YOU

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