SBAGNE news

Summer 2012 The Newsletter of the Spina Bifida Association of Greater New England

BEST
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YEARS

1971-2012

Notes from the Chair

by Matt Neal

A Little Preview

Since I've read this little gem of a newsletter and you probably haven't – here are some things to look for. We start off in the medical corner where Virginia Briggs, Ph.D., (I usually call her Ginny, being as we are married and all) summarizes some very relevant research on healthy pregnancies for women with SB. Take a look; it's a lot easier to deal with than reading through the original research paper.

Next, Alex Hooper makes the first of two appearances in this edition. Soak it up Alex; this is what fame feels like! Alex and his mom, Jessica Hall, each tell us a bit about what the 1st annual BEST weekend was like for them. We are so pleased that they made the trip down from Maine to participate! In his second appearance, Alex is named the recipient of this year's Jean Driscoll award – congratulations! Jean is an inspiring woman living with Spina Bifida who has won the Boston Marathon women's wheelchair race approximately 1 million times. We first met Jean back in the early 2000's when we (then known as MSBA) where given the opportunity to field a team in the marathon. Her vitality, drive, and tenacity were so inspiring that the Jean Driscoll Award was and is given each year to a person living with spina bifida who displays those same attributes. This year it's Alex – could it be someone you know next time?

There are also recaps of this year's Walk-N-Roll, Summer Picnic, and a little bit about the national SBA conference in Indianapolis (spoiler alert) – where SBAGNE received 2 fabulousness awards. Both the Walk-N-Roll and the Summer Picnic were held at the Mass Hospital School facility in Canton. We are quickly falling in love with this site – if you haven't been embraced by the comfortable waters of their beautiful and incredibly accessible pool, then you must make absolutely sure you come the picnic next summer!

Also not to be missed is the page on Team IMPACT. What a great idea! Parents, have a look on page 9. United Healthcare Children's Foundation is a charitable organization that grants money to families to cover healthcare costs beyond insurance coverage. I have used them to cover Grace's 2nd pair of braces one year, and I can vouch for the ease and rationality of the process.

We close with the inspiring autobiographical story by Hunimano Coelho, who was born with SB in Angola and migrated alone to Canada at the age of eighteen. Wow!

Helping Us Help

In the last note I talked about how the Walk-N-Roll event is a unique opportunity for SBAGNE constituents to reach out to their friends and family and help raise the funds that sustains our organization. This year's event was very successful both as a social gathering and a fundraiser. The final numbers aren't in yet, but it looks like we came very close to our very aggressive goal ($60,000). We have also just finished our Team SBAGNE participation in the Falmouth Road Race (details in the next newsletter). We have met our fundraising goal for this one ($40,000), with a few more donations still coming in! Well done Team! Again! In this one team members reach out to their friends and family to support SBAGNE. We have two more major fundraising events for this year, and the revenue from these four events form well over 90% of our budget for next year. That's how we work: raise it, spend it, raise it, spend it, etc. The third event this year is a Comedy Night happening August 24th, this new event is sold out and we are so excited about it! That leaves one more event to talk about, and really, this is where I was headed with this paragraph. It's our Annual Appeal, which will happen during Spina Bifida Awareness Month (otherwise known as October). This is our final opportunity to meet our goals for the year and build a budget for next year that does as much as this year's. We will be reaching out to you, our constituents, to make a donation to your association just because you believe in what we're doing together and you want to make sure we keep going. We'll do everything we can to make it easy to contribute – online, by post, or in person – so we'll be in touch in October and we hope to hear from you then as well!

Medical Research Corner

Striving for a Healthy Pregnancy in Women With Spina Bifida

by Virginia Briggs, Ph.D.

Many women with Spina Bifida (SB) have succeeded in having happy, fulfilling and healthy lives, despite the extra challenges of daily living. It is only natural that these women will also plan to raise a family of their own. It was once thought that women with conditions like Spina Bifida could not have a healthy pregnancy, and would not be able to care for an infant. In fact many health professionals and even family members may likely still feel that it is too difficult to attempt. However, with a greater understanding of the condition, it has been found that women with counseling and the right support system can do well.

A recent review published in the European Journal of Obstetrics and Gynecology, outlines some of the most important issues in maintaining good health during pregnancy in women with Spina Bifida. The most important consideration is managing urinary tract health, by avoiding infections. This is a little more complicated because some medications commonly used to maintain continence have not been specifically tested for safety during pregnancy. This should be discussed with the urologist before pregnancy starts, if possible. Also, since all pregnant women have a greater risk of urinary tract infections than women who are not pregnant, women with Spina Bifida have an even greater risk simply because of their condition. Pregnant SB women generally do not need to change their normal course of antibiotic treatment for UTI's, but should discuss their concerns with their urologists.

Another very important issue is the CDC's recommended dosage of folic acid in women who have a history of SB in their (or their husband's) families, including a previous SB pregnancy. This actually includes other types of neural tube defects (NTD's) which is the family of defects that SB is part of. It is best to discuss a history of any birth defects with their physicians to fully understand the higher risks involved. Because of this recommendation, SB women should consider themselves at higher risk for having an SB child. The great news is, SB and other NTD's can be reduced dramatically with the right amount of folic acid taken BEFORE getting pregnant and at least until the 12th week of pregnancy. It is highly recommended that women who have a history of SB should take 4-5mg of folic acid per day, which is ten times the normal recommended dose.

The article also reviewed the need for better counseling in girls and women who are sexually active. One study that focused on sex education in adolescents reported that girls felt they lacked education about specific problems such sexuality and handicap, fertility and heredity, latex allergy and condom use, incontinence and sexuality and social aspects of having a physical disability. These issues should be addressed by parents or other support systems such as the pediatrician to help adolescents understand and cope with growing up as well as they can.

Although there is no special protocol for managing pregnancy in women who have Spina Bifida, special attention should be paid to managing secondary conditions such as kyphoscoliosis, respiratory problems, spinal abnormalities, shunt failure and pressure sores, among others. It would be best for SB women considering pregnancy to consult with their regular physicians to discuss the specifics of their condition and plan how to manage potential problems before they occur.

REFERENCE:
Sexuality, pre-conception counseling and urological management of pregnancy for young women with Spina Bifida. Visconti D, Noia G, et al. European Journal of Obstetrical & Gynecology and Reproductive Biology. 2012 Apr 28.

ARE YOU OR SOMEONE YOU KNOW PASSIONATE ABOUT SBAGNE?

DO YOU OR THEY HAVE SKILLS THAT WILL HELP US FURTHER THE MISSION?

SBAGNE is currently seeking individuals who may have an interest in serving on the SBAGNE Board of Directors. Specific needs include individuals with skills in the areas of marketing, finances, development, event planning. Do you have other talents that will assist in furthering the mission, let us know.

If you are interested in receiving the Board Recruitment Prospectus, contact Ellen at **edugan@SBAGreaterNE.org.**

BEST Weekend a Success!

A mother and son's perspectives

by Alex Hooper and Jessica Hall

I enjoyed the weekend. It was all stuff I liked to do, swimming, basketball, baseball, bowling (which was my favorite). I liked the vehicle displays, especially the motorcycle. The reki session was interesting, I learned some breathing techniques and stuff to calm myself down before medical procedures. The goody bags were neat and I liked the talks but for sure I enjoyed playing the sports the best.

Alex Hooper

My son and I attended the boy's BEST weekend, it was a long drive for us but definately worth it. The thing I liked best about the weekend was the educational seminars, I feel knowledge is power. I also thought it was great to have someone there with Spina Bifida who was very inspirational and able to speak with the boy's about various things including not limiting yourself and living life to the fullest. I also feel it is important for my son to be able to socialize and meet other's who are/have gone through the same exact things in life as he is going through. We live in a very small town and sometimes he feels like he is the only one going through this stuff. Sports, learning, food and fun; couldn't of asked for a better weekend. We are looking forward to attending next years boy's BEST weekend. Thank you for having this event!

Jessica Hall

2012 BEST Participants

WALK-N-ROLL a Grand Success because of You!

WALK-N-ROLL for Spina Bifida

On June 16, the Spina Bifida Association of Greater New England held our 3nd Annual Walk-N-Roll for Spina Bifida at the Mass Hosptial School in Canton, MA. Over 250 participants from all over New England came out for this family-friendly event.

Led by "Paws," the Pawtucket Red Sox mascot, Walkers and Rollers took on a 1.5 mile course and helped build awareness about Spina Bifida. Following the walk, Walkers and Rollers were able to connect with members of the community. This was not only a fundraising event, but a celebration!

The Walk-N-Roll for Spina Bifida is being held in various locations across the country to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with it. All proceeds are used for programs and services for people living with Spina Bifida.

The name "Walk-N-Roll" was selected because it embodies a sense of inclusiveness and invokes the sense of empowerment which the Spina Bifida Community embraces in all that it does. A belief in a better tomorrow is our vision and the steps taken in this walk represent steps on a path to realizing that dream.

Over $55,000 has been raised for the Spina Bifida Association of Greater New England through the Walk-N-Roll for Spina Bifida. This is a remarkable amount!

Donations are still being accepted at **www.walknrollsbagreaterne.org**.

Thank you to all who participated and volunteered! You made the Walk-N-Roll a success!

Plans for the 2013 Walk-N-Roll for Spina Bifida are already underway. If you would like to be a member of the Walk-N-Roll Committee or would like to volunteer, contact **Wendy Potts** at **wpotts@SBAGreaterNE.org**.

SBAGNE Receives 2 Awards at SBA National Conference

On Sunday July 1, 2012 SBAGNE received 2 awards at the SBA National Conference Celebration Luncheon held in Indianapolis, IN. SBAGNE received the Partnership/Collaboration Award for our alliance with SBA of Connecticut in hosting the New England Spina Bifida Conference in October 2011. The criteria for receiving the award included: whether the partnership is a good model for other chapters to replicate, can the partnership be sustained beyond the first year and do each of the organizations and their constituents gain from the relationship.

SBAGNE also received an award for the Greatest Percentage of Growth in Income between the 2010 and 2011 Walk N Roll events. We received this award due to the enthusiasm and commitment to SBAGNE on the part of our constituents, their families and friends. THANK YOU to all!


3GIRLS A GUY


VERONICA'S ANGELS


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3GIRLS A GUY
2012 SBAGNE WALK-N-ROLL
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therockchurch

CONGRATULATIONS TO ALEX HOOPER OF SEARSPORT, ME
2012 JEAN DRISCOLL AWARD RECIPIENT

Alex is currently a student at Searsport District High School, Searsport ME. Alex wrote in his application that he is an active participant in his community. At Thanksgiving and Christmas he has helped pack over 1000 food baskets for those in need, helped make and sell items and was able to contribute more than $400 worth of toys to Wings of Love. Alex is also an Eagle Scout.

In addition Alex made honors each trimester during the past school year. He also received the school citizenship award for organizing a school assembly with Chris Waddell presenting. Chris is the first paraplegic to climb Mt Kilimanjaro. Alex is active in his church as a volunteer with Sunday school, supers and coffee hour. Alex's interests include hiking, baseball, wheelchair sports, rowing, downhill skiing and many others.

Alex's recommendation reads in part "Alex is a hard working individual who strives to succeed in spite of his physical challenges. He is very independent and strong willed. When he identifies a goal he puts 100% of his efforts to achieve it. Alex's natural ability to lead relates to his ease and comfort in talking to people."

Alex's "dream big" goal is to start an adaptive adventure company. He would provide accessible adventure excursions worldwide.

SBAGNE is pleased to be able to honor Alex as the 2012 recipient of the Jean Driscoll Award.

Thaddeus Medeiros Throws out First Pitch at Spinners Game!

SBAGNE Summer Picnic - Fun for All!

Sunday, On July 8, SBAGNE held its annual Summer Picnic at the Mass Hospital School in Canton. Over 60 individuals and families attended the event. It was a perfect day to celebrate summer, meet new friends and reacquaint with old friends.

After enjoying some great food and ice cream sundaes, families were able to cool off in the accessible pool. Later in the day, everyone was able to take a ride on an accessible pontoon boat. Unfortunately, the boat lost power mid-ride and folks were "stranded" on the lake for a bit. Thanks to a good neighbor with a jet ski, the boat was dragged back to shore! Just a little excitement to make the day even more memorable!

WE COULDN'T DO IT WITHOUT YOU!

On May 20th Kim and Hannah Farrell hosted what has become an annual fundraiser in support of SBAGNE. Held at Jenny Boston Boutique, 20 % of sales are donated to SBAGNE and attendees leave with some great accessories! Arbella Charitable Foundation also supports this annual event. Thank you to Kim, Hannah, Jenny Boston and Arbella.

Elizabeth Brodeur, Intern, has been working at the SBAGNE office since January. As part of her job placement program Elizabeth has assisted with mailings, preparation for the Walk N Roll, and general office administrative tasks.

On June 16th SBAGNE held the 3rd Annual Walk N Roll for Spina Bifida. We would like to thank the top 3 teams: Olivia's Smile, 3 Girls and a Guy and the top 3 fundraisers: Genevieve Medeiros, Jessica Guest and Brandon Casten. SBAGNE would also like to acknowledge Jim Fallon and Donald Smith who took photographs day of the event. Thanks to Judy and Joe Potts for their help at the Walk and continuing support of SBAGNE and to Shauna Stephenson who assisted with public relations for the event.

Thank you to our Walk-N-Roll Sponsors!

Silver Sponsors

Ampramp
Perez Gardini LLC
Ride Away
SB Genetics
Stop and Shop
Wilmington Medical Supply

Exhibitors

Hollister Medical
MIX 104.1
Polar Beverages
Powerade
Pawtucket Red Sox

Team IMPACT: Profile
Nick: The Youngest 6th Man in the NE-10

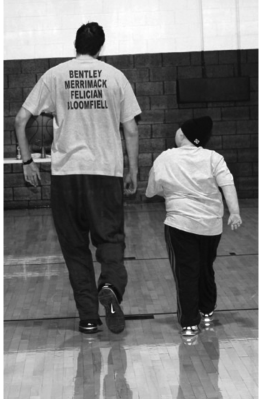
As a member of the Boston Celtics in the 1980s, Larry Bird won three NBA Championships and was named the NBA's Most Valuable Player three years in a row. His basketball prowess can be accredited to his incredible work ethic and drive, but there is one trait that Bird possessed that separates all of the best athletes apart from the rest- the ability to make his teammates on the court better. In basketball, each and every member of the team has a role that helps determine a team's success. Some players are relied upon to score clutch baskets where others are asked to battle under the basket in order to come up with the rebound. The Merrimack College men's basketball team is no different. The 13 members that make up the team's roster are all asked to play their role to the best of their ability – relying on their teammates to do the same. Yet unlike most basketball teams, there is one team member on the Merrimack squad who will never set foot on the court during a game but plays just as an important role as his 12 other teammates – 10-year-old Nick.

Nick is a 6th grader from Methuen, MA who on January 27, 2012 became the newest and youngest member to join the Merrimack basketball roster in the school's history. In September of 2011, Nick was diagnosed with Hodgkins Lymphoma, a cancer in the lymphatic system that is part of the immune systems that fights off infections and diseases. Hodgkins Lymphoma, like other blood cancers, requires treatment consisting of both chemotherapy and radiation. For Nick, this meant that upon his diagnosis in September, he would have to spend the next 4-6 months at the Dana-Farber Cancer Institute receiving treatment, leaving behind his typical routine he once knew.

In order to receive chemotherapy, Nick had surgery to implant a port into his chest that allows the chemotherapy direct access to his blood supply. The port, which is under the skin, is then accessed by a two-inch needle that acts as an IV that supplies the life-saving medicine at each of Nick's treatment sessions. Following a grueling three month cycle of chemotherapy and steroids, Nick then moved on to a month of radiation which involved multiple visits a week to Dana-Farber requiring him to miss more school. Away from his friends and classmates and confused to why cancer had chosen him, Nick buried himself in the one thing that has always made sense – sports.

It is through Nick's love for sports that he became aware of Team IMPACT and soon thereafter became a member of the Merrimack basketball team. After being referred to Team IMPACT by Lisa Scherber, the Director of Patient and Family Programs at Dana Farber, Nick was matched up with the Merrimack basketball team and joined the 2011-2012 roster. On his Draft Day, Nick and his mom, Anne, met the team at a practice in their home gym, Hammel Court. Before heading out to the gym, Nick met with his new head coach, Bert Hammel, and was quickly covered from head to toe in Warrior navy and gold with t-shirts, a hat, and sweatshirt. Ready to meet the team, Nick entered the gym with butterflies in his stomach – both excited and nervous to meet his new teammates.

Any nerves that Nick had prior to walking through the gym's double-doors faded as he watched his 12 basketball brothers take to the court to start practice. Within minutes, another member of the team that was not going to take to the court, the injured 7-foot center, Juan Rosich, came over to Nick and scooped him up to teach him how to control the clock for practice. Sitting with Juan, Nick could not help but smile as he helped keep track of the points and the time as the rest of their teammates worked through different drills and plays. Nick and Juan then started shooting baskets themselves- Juan towering over Nick as he shot, and Nick, with his Merrimack hat pulled down over his bald head, never losing focus.



For more information visit **www.goteamimpact.org**.

Team Impact is a non-profit organization whose mission is to improve the quality of life for children with life threatening illnesses or disabilities. If you and your child are interested **Team IMPACT** can be reached at **info@goteamimpact.org** or by phone at **617-801-0248**. Ask to speak to either Bryan or Maura.

Upcoming Events & Opportunities

Grants for Children's Healthcare Treatments

The **United Healthcare Children's Foundation** is seeking grant applications from families in need of financial assistance to help pay for their child's health care treatments, services or equipment not covered, or not fully covered, by their commercial health insurance plan.

To be eligible for a grant, children must be 16 years of age or younger, families must meet economic guidelines, reside in the United States and have a commercial health insurance plan.

Qualifying families can receive up to $5,000 to help pay for medical services and equipment such as physical, occupational and speech therapy, counseling services, surgeries, prescriptions, wheelchairs, orthotics, eyeglasses and hearing aids. Grants are available for medical expenses families have incurred 60 days prior to the date of application as well as for ongoing and future medical needs.

Parents or legal guardians may apply for grants at **www.uhccf.org**.

SAVE THE DATE

Saturday, September 22, 2012
8:30 AM - 4:30 PM
New England Spina Bifida Conference

Sturbridge Host Hotel and Conference Center
Sturbridge, MA

Massachusetts Family-to-Family Health Center Information Center

The Massachusetts Family-to-Family Health Information Center, is a FREE parent-run project at the Federation for Children with Special Needs, that advises families on how to receive benefits and to qualify and apply for MassHealth. In addition, they assist families with children and youth with special healthcare needs in accessing public and private health insurance benefits, community resources, offer a listserv, an annual family conference, conference calls, and host workshops about healthcare financing. Visit **www.massfamilyvoices.org**, or contact project director **Beth Dworetzky** at **(800) 331-0688, ext. 210** or **massfv@fcsn.org**.

Thank You to Bain Capital

Each year **Bain Capital employees** may nominate a charitable organization that supports the general welfare of children and young adults. Monies were raised through the Bain Capital Children's Charity Golf Event which took place this past September 2011. SBAGNE was selected because of our commitment to supporting the general welfare of children and young adults.

Thank you to Children's Orthopaedic Surgery Foundation for their ongoing support of SBAGNE

I am me, but also you

by Hunímano Coelho

I rarely think about my Spina Bifida anymore.

I was born in Angola, Africa in 1981, to very young parents who were barely prepared to have their first baby. I was born at home premature by a month. Once at the hospital I was diagnosed with Spina Bifida and with congenital bilateral hip dysplasia (I also have severe scoliosis). I had my first surgery when I was a day old. After that I had surgery on both my feet and an unsuccessful attempt to have my hips fused. By the time I was eight years old my lower body was filled with the scars of surgery.

Growing up with a disability in a country where there was barely any system or infrastructure to help people with disabilities was, and still is, very challenging. There are very few options available to us even on the small basics like healthcare, education, employment, etc. However, rather than allowing me to fall through the cracks of our society, my parents took to task and ensured that I would not only survive but that I would also excel in life. Along with my healthcare, my education was top priority on their list. To my father it did not matter that the schools I attended as a child had stairs and that I was on crutches. It did not matter that washrooms were not accessible and I had to go on schedule or face wetting myself. He had to be the tough one to make sure I learned my lessons and didn't become dependant on anyone. Throughout my childhood my parents instilled a very simple message to me: There is no sitting on the sidelines because of my disability, no giving up, and I must always try and do my best, just like everyone else, and when I can do better than everyone else. Not because I had to but because I could. Our society was not setup for people with disabilities in mind. That leaves you no option but to do like everyone else. You adapt to what works, push as much as you can and life goes on.

I did not get a chance to participate n physical education at school. My father taught me how to swim when I was about six, and since then I have enjoyed swimming in the beautiful south Atlantic with my friends and family. And while most people my age were out and about having fun I delved deeply into an array of books. Jules Verne, Ernest Hemingway, Mark Twain, tons of encyclopaedias, to name a few. Thanks to all the spaghetti westerns I grew up watching I decided to learn English. One of my aunts had course on LP and quite a few books on the matter. So I learned English. I was semi-fluent by the time I was ten, fully fluent by 14 and by 16 also spoke Spanish and French and of course Portuguese is my first language. I have travelled to Europe, many times, been to Brazil and Cuba, but had never come to North America. When I completed my HS in Angola, I knew that my options in the country were limited. Despite my skills and abilities the reality of society's stigmas was too obvious to ignore. So I decided to migrate and take on the challenge somewhere I would have more parity with society at large. It wasn't the venturing part that was difficult for my parents but the going alone into a completely different country so far away from them. But they knew I had the drive in me, not to mention all the amazing lessons I learned from them.

I migrated to Canada when I was 18-years-old without fully understanding how much it would change my life. Having arrived without knowing anyone I lived in a youth shelter for year. Within six months of my arrival I took my first job as a telemarketer. It was quite the experience. The day I received my first paycheque was one of the most memorable ones from my early days here. I also had to go back to high school to meet the Canadian equivalence. And for the first time in my life I started meeting people on the street who kept on telling me how inspired they were to see me going to school and holding a job. I never quite understood that because to me I was just doing what everyone else was doing, trying to live life and make ends meet. A few years after being here I established contact with the SBHAO. For the first time in my life I obtained so much information about my disability that I was almost overwhelmed. However, I never fully took advantage of their resources and did not pursue on the subject any further. I was always too focused on the matters at hand. I moved from the shelter and between social assistance and part-time work and full-time school I graduated from high school. I took a legal assistance course through correspondence and decided to look for work in the field. It was only after completing high school and trying to find full-time employment that I was able to fully understand the level of discrimination and difficulty that people with disabilities face when it comes to finding employment. Up to that point I had taken part-time jobs primarily in telemarketing or data entry. Those are relatively easy to enter. It was meeting interviewer after interviewer and seeing the same look in their faces, the look of shock and surprise, the feeling of pity in the air. It was a difficult period for me, having to accept that despite all my skills and willingness to learn and adapt that people would still look first and foremost at my disability rather than what I had to offer. But I persisted. I was able to get a temporary legal assistant position for a small immigration firm in midtown Toronto. And by 2005, I was able to secure employment with Michael Korman who, coincidentally, helped me with my immigration matters. In him I found an employer that not once brought my disability as an issue and treated me like everyone else. He soon became my mentor and a good friend.

Once I started working full-time and was able to become completely self-sufficient I took on other challenges. I learned to drive and bought a car. Also I was now able to fully enjoy things that I had wanted to do for years. Went sky diving, did road trips. I started doing indoor rock climbing, sailing, skiing, and scuba diving. I became more engaged in the community at large volunteering my time and experiences with various organizations. As I continue to grow as an individual, I look forward to further challenges in my career and in life. I decided to go back to school. I am now completing my first year, double major in Political Economy and Psychology, at Athabasca University.

My upbringing makes me think of my disability differently than what I have grown accustomed to hearing from people here in Canada. It is part of who I am, and that I cannot change, and don't want to change. To quote my parents, "always try and do your best, just like everyone else, and when you can do better than everyone else."

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Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with Spina Bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of Spina Bifida is growing rapidly and all data are subject to change without notice. Neither the SBA of Greater New England nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The SBAGNE does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. The SBAGNE does not employ medical personnel in its organization.

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