news

sbaMass

Spring 2009 The Newsletter of the Spina Bifida Association of Massachusetts

Letter from the President

by Brendan Sullivan

Hello again! I hope this edition of the sbaMass newsletter finds you thawing from another New England Winter and ready for the warm weather that will beckon shortly.

In this newsletter, you will find much information about our summer events including our annual picnic, the annual SBA National Conference, and a mini-golf tournament we are planning in the fall. I hope you enjoy reading about these upcoming opportunities to gather as a community, and most importantly I hope that you can join us for all of these activities in the coming months.

Finally, in today's economy I want to remind everyone that financial help is available through the sbaMass Benefits Program. This program can aid in uncovered medical bills and other expenses related to Spina Bifida incurred by individuals or their families. Be sure to review the benefits application within the newsletter for more information.

I wish you a warm and healthy spring and I look forward to welcoming you to our many events in the coming months.

sbaMass

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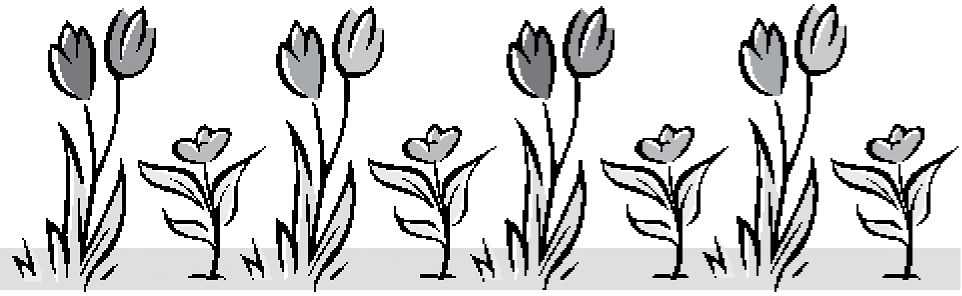

Get Ready to Run for sbaMass!

Year 3 promises to be better then ever!

If you happen to be in or near **Falmouth, MA on August 9**, please come cheer on Team sbaMass as they run the Falmouth Road Race. For the past three years sbaMass has been fortunate enough to gain charity entries to the Falmouth Road Race, a beautiful 7 mile course along the shores of the Cape in Falmouth, MA. Our team is easy to find in their bright blue singlets with orange racing flames on the sides. They give us a boost, not only financially, but also by bringing attention to our organization. We hope that this year's Road Race will be another successful day for Team sbaMass.

Over the past three years, our dedicated members of Team sbaMass have raised more than $75,000 for our organization. The runners ask for donations to support their run, and have succeeded in greater numbers each year. We hope that 2009 will follow the trend. The day brings much more than financial success. Our Team members have found the entire experience to be very rewarding in so many ways: from the satisfaction of finishing a 7 mile race, hearing the cheers along the way, being part of a fun-loving team with a great post-race party, raising money for so many who need help and knowing they have done a job well. We are so thankful for all their hard work. We would love to have any supporters out there join is in cheering the runners on the course.

If anyone you know might like to be a part of the team, please e-mail Cara Packard at **cpackard@sbamass.org**. We hope we'll see you on race day along the course!

Road Race Facts

- **The race was founded in 1973 and had 92 finishers. This year's race will be the 37th.**
- **The race is a non-profit, tax-exempt corporation. Proceeds are used to support youth athletic programs in the Town of Falmouth and for the benefit of other non-profit community groups.**
- **The length is seven miles and the route is along the shore from Woods Hole, around scenic Nobska Lighthouse Point, along Surf Drive and around Falmouth Harbor, finishing at the beach in Falmouth Heights.**
- **10,000 official entrants and many unofficial "crashers." Spectator crowd has been estimated at 75,000+.**
- **Considered to be one of the premier sporting events in New England.**

For a complete list of upcoming sbaMass events, please see page 10 of this newsletter.

Update

The sbaMass Annual Golf Tournament

The 5th Annual Golf Tournament is being downsized, like much else in our world!

The sbaMass has decided to put the Golf Tournament held at Sky Meadow each year on hold until 2010.

Instead, the **sbaMass will hold a Mini Golf Tournament on October 17th from 2-5 pm at Trombetta's Farm (which is a handicap accessible indoor course so no weather worries!) located in Marlborough MA.**

This will be a family-friendly event to raise funds for the sbaMass and awareness of Spina Bifida during October, Spina Bifida Awareness Month. Look for more information on www.sbaMass.org and in the Summer newsletter.

Managing Systems ---Loving Your Child---Being at Peace: Unveiling and Exploring the Unique Stresses of Parenting a Child with Spina Bifida

On **August 15th from 12:30 – 4:30**, Alaya Chadwick, M. Div, MSW, LICSW, BCD will be offering a session for parents of children with Spina Bifida. Focus will be on the stresses that may come from feeling a big sense of responsibility to make choices in the best interest of your child while managing a myriad of other systems and meeting the needs of other family members. This will be a 4 hour session where parents will learn simple and practical ways to be more peaceful in the midst of what can be chaos. Space will be limited – Look for more information in July.

My 6 Favorite IEP (Individualized Education Programs) Resources

by Joan Celebi, Ed.M., CLC
Founder, SpecialNeedsParentCoach.com

I've been getting lots of calls and emails over the past few weeks from moms and dads looking for information on IEPs, so I thought I'd put together my favorite IEP resources in one article for easy reference. These 6 are all you need to make sure you've got the best IEP possible for your child.

1. The Complete IEP Guide: How to Advocate for Your Special Ed Child, by Lawrence Seigel - up-to-date, easy to understand, and packed with sample letters, timelines, checklists, etc. Read this book and you will know exactly what you need to do to get the right special education services for your child.
2. The Wrightslaw Website - the first place I go when I have a question about special education law. (**www.wrightslaw.com/info/iep.index.htm**)
3. Precision Education - sign up for IEP expert Catherine Whitcher's newsletter and receive a handy IEP Checklist. (Scroll down to the bottom of the home page for the newsletter sign-up box.) Catherine can also work with you if you need help with your IEP.
4. Special Education Advocates - not sure where to find an advocate in your area? Start with Wrightslaw's Yellow Pages for Kids. Advocates are trained to know special education law and guide you through the IEP process.
5. Other parents - contact other parents from your school district who have children on IEPs. Fellow parents can be an invaluable source of information, resources, ideas, and experience. It also helps to have the support and encouragement, too, of just talking with someone who can relate to what you're going through and all that you do.
6. And don't forget Your IEP Action Plan: 16 Strategies for Surviving Your Next IEP Meeting - one of the most popular articles here at SpecialNeedsParentCoach.com, with practical things you can do to make life run more smoothly and to maintain your inner calm -- before, during, and after an IEP meeting.

Joan Celebi is the founder and president of SpecialNeedsParentCoach.com, and the author of Overwhelmed No More! The Complete System For Balanced Living for Parents of Children with Special Needs. You can subscribe to the Free Overwhelmed No More! Newsletter, and Joan's blog, The Special Needs Parent, at **www.SpecialNeedsParentCoach.com** (click on "Free Resources").

Advocacy

by Ellen Heffernan-Dugan

On February 26th I spent the day in Washington DC meeting with the offices of Massachusetts' Representatives Richard Neal, John Olver and Senators Kennedy, and Kerry. The primary focus of the meetings was to call upon Congressional members to support the following:

- $7 million for the National Spina Bifida Program at the Centers for Disease Control (CDC)
- Increased funding for the CDC's national folic acid education
- Increased funding to strengthen the CDC's National Birth Defects Prevention Network
- Enhance and ensure quality of life for all individuals affected by Spina Bifida including comprehensive private and public health insurance
- Provision of durable and non-durable medical equipment through private and public insurance
- Comprehensive information to reduce secondary effects and complications of Spina Bifida
- Provision of training programs and related services.

Although these are difficult economic times, SBA and sbaMass firmly believe in our mission "to promote the prevention of Spina Bifida and to enhance the lives of all affected". If you are planning to visit Washington and are interested in visiting the Washington office of your Representative or Senator, contact the sbaMass office a edugan@sbaMass.org or 888-479-1900. If you would like to visit the local office of your Representative or Senator please contact. SBA will provide the necessary information. Time spent on Capitol Hill or visiting the local offices of your Congressional representatives is time well spent.

Insights Subscriptions

The sbaMass regretfully announces that the next issue of Insights Magazine will be the final complimentary issue that it will provide to all members. The decision was made due to the cost of providing this service in an uncertain economy and due to the lack of member response to last year's survey regarding the continuation of this service. If you are interested in continuing your subscription to Insights, you may place an order through the SBA National office, either on the website marketplace at **www.spinabifidaassociation.org** or by phone at 800-621-3141. The cost of an individual subscription is $25 for one year.

Right Under My Nose was created to help children with Spina Bifida understand their condition, discover new ways to enrich their lives and help their parents and caregivers answer many of the touch questions that arise. With a fully interactive story, activities, tips and a printable version of the whole book, this site is intended to be educational and fun. Enjoy! Log onto **http://myspinabifidabook.org**.

Parking Pads are available for free download through the United Spinal Association - "Parking here for just a minute" ... is 60 seconds too long! Log onto **www.unitedspinal.org/pdf/parkingpad.pdf.**

“How To” File an Appeal

by Linda Jorgensen

Recently I had a telephone conversation with one of the managers of our state’s Bureau of Coverage and Reimbursement for Medicaid. That office is responsible for reviewing all appeals for denied Medicaid medical claims in the state. ***The most common mistake people make when receiving a denial of benefits is failing to file an appeal!*** In our state the vast majority of appeals are approved, provided they have been submitted properly and provide necessary information proving medical necessity.

A denial often means the insurance provider needs more information than they have been given.

Medical claims are denied for a wide variety of reasons with the most common being failure to provide enough information regarding the requested benefit to prove medical necessity. This is especially the case with high dollar medical equipment, palliative care, and other treatments specifically identified by the insurance company. It is important to remember you are dealing with individuals who don’t know you, don’t know your child and most likely don’t have enough information regarding an individual’s medical condition and status, why the item(s), treatments, cares, etc. are medically necessary and what possible outcomes may be expected if the individual does not receive the requested benefit.

By following the approved appeals process many individuals will obtain approval for the services or equipment they need. **Always appeal a denial.**

It is important for you to be familiar with the appeal process required by your insurance company. Not all companies follow the same appeal process. Most companies include a section in their beneficiary manual on “How to File an Appeal”. Many companies also include that information on the back of their Explanation of Benefits (EOB), or in the fine print of any claim summaries you may receive. If you cannot find appeal instructions call the insurance provider’s Customer Service number and specifically request information on how to file an appeal.

There are seven basic steps in filing an appeal. Each step is important and should be followed in order. Generally, the vendor who will provide the equipment or service will also be assisting you in the appeal process.

The most common mistake people make when receiving a denial of benefits is failing to file an appeal!

- **Step One: Review your Benefits and Policy Manual.** The first step in launching a denial appeal is the same as filing the claim in the first place. Was there something there that you missed? Did you read the fine print? Are you sure of the detail? Did you need a preauthorization and fail to get one? Having a firm understanding of your policy will help you know what questions need to be asked.

- **Step Two: Contact your Insurance Provider.** If your claim has been denied be certain it was denied by the appropriate person. Often times insurance company personnel will tell you “no” when in reality they do not have the authority to do so. Be sure the decision came from the right office. **Don’t take “No” from someone who isn’t authorized to say, “Yes”.** When you call to verify information be sure to document all pertinent information you discuss. I recommend using an SNRP Call Form. Be sure to document all of the following on your call form or in your notes if you are not using a call form:

- Company name.
- Date and time the conversation took place.
- Name and title of the person you talked to. Be sure to note any other individuals you may talk to during your call.
- Account number and any questions you may have regarding the claim in question.
- Write a detailed summary of what was discussed and any instructions or information you were given.
- Obtain a confirmation number for the call, if your company provides one, once the call is completed. This will be used as a reference by case management in future follow up action.

- Write a short summary of any decisions or agreements reached.
- Be sure to add your signature to the bottom of the page. This could always be used as a legal document later, if needed. Information on this document may be used as part of the documentation packet submitted with your appeal letter. Remember. ***"If it isn't on paper, it didn't happen".***

- **Step Three: Ask for help.** Once you have contacted your insurance provider and identified the process to follow you ay need further assistance in proving your case. If so, get help. Contact your Primary Care Physician and any other related specialists. Specialists may include therapists, school staff, home health nurses, lab reports, second opinions from other physicians, etc. Tell him/her you are appealing a claim denial and need assistance. Ask for a detailed letter of medical recommendation, medical necessity, medical records, care notes or any other information requested by the insurance company that may aide you in stating your case.

  Still need help? Contact your company Human Resources Office and ask for assistance in mediating an insurance claim denial. Many companies have an insurance mediator assigned to assist employees with difficult medical claims. They are also good at reading the fine print.

- **Step Four: Write your letter of appeal.** Be sure to be clear and concise. State you are requesting an appeal, and why. Attach any new information, treatment records or detailed letters from your physician or other providers regarding the request. Many times important detail has been left out of the first authorization request and more detail is needed. This is the time to use the documentation you've been keeping. Copies of phone conversations (completed call forms), letters you may have sent, bills, EOB's, letters of denial, etc. can all be used in the appeal process. Be sure to outline the steps you have taken and list the documents you are attaching for review.

- **Step Five: Submit your appeal.** Once you have gathered all your supporting documentation, asked for help and written your letter it is time to submit your appeal packet. Make copies of all documents in your appeal package. If sending by US Post, send the packet with a Delivery Confirmation slip and tracking number. Be sure to file this information with your copy of the packet. If you are faxing your information be sure to retain your fax confirmation sheet.

- **Step Six: Track your appeal!** Be persistent in keeping track of where in the process your paperwork is. Many companies will assign an individual case manager to appeal cases. Be sure to stay in touch with your contact person. Don't lose your appeal by letting it "fade into the paperwork pile" on someone's desk. With many large companies an appeal could take a few weeks or even a few months. Most folks think, "No news is good news". No news could mean trouble. Ask your case manager if there is a time limit. If a deadline is approaching and you still haven't heard anything, call and ask for a status, or progress, report on your appeal. The biggest majority of folks who lose out on benefits don't lose them because they are denied it's because they fail to follow through. If you want that medical equipment paid for appropriately you're going to have to follow through until you have that determination letter in your hand.

- **Step Seven: Document the outcome.** Once an appeal has been denied it becomes your responsibility to find alternate resources for funding. Every time you receive a denial from someone, KEEP IT! A denial for a medical claim will give you extra leverage when filing for other assistance programs and justification for financial assistance programs. DENIALS ARE GOOD! They are the evidence which proves that you really have tried other avenues and really do need assistance from other sources. Without them you only have your word that you tried your insurance provider first.

I know, I can hear parents groaning about paperwork and bureaucracy but it is often imperative to go through the denial process in order to get other services available. If you want the services you need you have to fight for them. Unfortunately paperwork is a part of the system we have to deal with. If, at first, you don't succeed, file an appeal. Don't wait, just do it.

Thanks to the Special Needs Resource Project at www.SNRPROJECT.org for allowing us to reprint this article.

SBA National Conference - Orlando, FL June 30th- July 3rd

SBA's National Conference has earned its place as the world's premier conference serving the Spina Bifida Community. Don't miss this year's 36th National Conference June 30 - July 3 at the Walt Disney Swan and Dolphin in Orlando, Florida.

Can't Miss Conference Programming

- Exceptional Medical Sessions
- Practical Workshops
- Distinguished Presenters
- Memorable Social Events

Who Should Attend?

- Adults with Spina Bifida: Gain vital information about making the most of your life and health.
- Parents of Children with Spina Bifida: Learn innovative ways to help your children grow into independent and active adults.
- Children with Spina Bifida: Experience the fun of Kids!Camp. Learn from other kids how much you can accomplish while having the time of your life!
- Medical Professionals: Sharpen your clinical skills and gain insight into cutting edge therapies.

Log onto www.sbaa.org for more information

Is This Your Year to Dream Big?

The sbaMass Board of Directors has revised the Jean Driscoll Scholarship for 2009, renaming it the Jean Driscoll Award. The award may be used for future educational pursuits, camps or training courses taken to improve the applicant's skills in an area of interest to the applicant. The award will be granted to a person, age 14 though adult hood, who, like Jean Driscoll, is achieving his or her goals despite any limitations imposed by Spina Bifida and who best demonstrates the character and determination of the awards namesake.

Jean Driscoll, who was born with Spina Bifida and has used a wheelchair since her early teenage years, is an accomplished athlete and speaker known around the world. She has enjoyed a life many people can only dream about experiencing. Jean is an Olympic athlete who has won Silver medals in both the 1992 and 1996 Summer Olympic Games. She is a world record holder in the 10,000 meter track event, 10K and marathon road racing distances. She has won the Boston Marathon eight times and is the only person in Boston's 105 year history to achieve this feat. She even has a street named after her in Champaign, Illinois and a park pavilion named after her in Urbana, Illinois. For more information about Jean Driscoll to understand the nature of this award, please feel free to review the following: **www.jeandriscoll.com.**

Look for additional information about the award in the Spring sbaMass newsletter and on the sbaMass website, **www.sbaMass.org**.

Mark Your Calendars for the

Seventh Annual sbaMass Summer Picnic

Saturday, July 18, 2009

12:30 pm - 4:30 pm

Cambridge, MA

Parking Lot and Picnic Area
near the office & restrooms

Map, Directions Can Be Found At
www.sbamass.org

- ***Food and Beverages***: Lunch will be provided.
- ***Please bring*** sunscreen and a lawn chair (if you prefer a chair to the grass!).
- ***Picnic Fun***: Activities and surprises for all ages.
- ***Other activities*** at Danehy Park include a water spray park, playground, and numerous sports fields.

AccessSportsAmerica, a national non-profit organization founded in 1995, inspires higher functin and fitness for children and adults of all disabilities thorugh high-challenge sports. We adapt sports that the most agile of athletes find challenging and bring these sports to children and adults with disabilities. Visit **www.accesssports.org**!

Do you have items to donate? Let us know and we'll include them in the sbaMass newsletter and website.

Contact Ellen Heffernan-Dugan at **edugan@sbaMass.org**

2009 Calendar

(All dates subject to change)

May

Saturday 5/2 – YAG Lunch
Saturday 5/16 – Teens Group (ages 13-17)

June

Saturday 6/13 – YAG Lunch
Sunday 6/28 – Friday 7/3 – SBA National Conference, Orlando, Florida

July

Tuesday 7/7 – Board Meeting - 7PM
Saturday 7/18 – Summer Picnic
Monday 7/20 - Golf Tournament

August

Sunday 8/9 - Falmouth Road Race
Saturday 8/29 – YAG Lunch

September

Saturday 9/12 – Teens Meeting

October

Saturday 10/3 – Tween Meeting (ages 7-12)
Tuesday 10/6 – Board Meeting 7PM
Saturday 10/24 – 5th Annual YAG Lunch and Learn

November

Saturday 11/14 – Parents of Young children (newborn-age 6)

December

Sunday 12/6 – Holiday Party

Dates to be determined:
*Red Sox Community Home Stand
*Lowell Spinners Family Day

Check the website (**www.sbaMass.org**) for updates and changes

sbaMass constituents should review all benefits requirements, before submitting applications, as some requirements have been changed for 2009. Please contact Ellen Heffernan-Dugan at edugan@sbaMass.org or (888) 479-1900 with any questions.

Contacts

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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 Massachusetts nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The sbaMass 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 sbaMass does not employ medical personnel in its organization.

sbaMass has a New Home!

On January 1st, sbaMass moved into office space at 321 Fortune Blvd in Milford, MA. The office is close to the Mass Pike and just off Rte 495. This move to space outside of volunteer and staff homes has been much anticipated. Although the office is not large, approximately 300 sq ft, it is hoped that sbaMass will be able to have some of our upcoming events and meetings there. The office is on the first floor of a medical/professional building, fully ADA accessible with ample parking. Our local phone number is 508-482-5300, or fax number is 508 -482-5301. You may still reach us on our long distance number (888-479-1900). If you are in the area, please stop by. Ellen is generally in the office on Tuesday, Thursday and Friday, but call before you come by just to be sure.

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