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Winter 2010

The Newsletter of the Spina Bifida Association of Massachusetts

Benefits Programs Update

Happy New Year to all of you. We hope that 2010 finds you healthy and happy. As the New Year kicks off, we would like to bring your attention to some changes that will be afoot regarding our Annual Benefits Program.

We are thrilled to report that in 2009 our Benefits Program was able to assist more applicants than ever. We saw increases of nearly 50% in the number of applicants to the program. We are so happy to see that our outreach efforts are reaching so many of you. As we continue in 2010, we want most of all to be able to ensure that we can provide assistance to each of our qualified applicants. However, in order to ensure that we are able to most fairly assist the largest amount of applicants while maintaining our budget, the sbaMass Board has approved changes to the benefits program. These changes will allow our organization to properly plan for continued growth without limiting the number of applicants to our program. We hope that some of these changes will make it easier for the applicants as well.

Our 2010 Benefits Policy will be posted to our website www.sbaMass.org by early February. Once the policy is posted, applications may begin. Until that time we ask for your patience and understanding as we work to best help you..

sbaMass Quarterly News

The sbaMass Quarterly News will be changing its distribution schedule for 2010. This change will allow sbaMass to get information out to members of the Spina Bifida Community in a more timely manner. The Quarterly News will be distributed in March, June, September and December. A reminder that www.sbaMass.org has up dated information regarding events, benefits and additional resources. Thank you for your understanding

sbaMass Committee Needs

sbaMass is currently seeking additional volunteers for Board Committees. Committees generally meet 4-6 times per year, typically in the evening, and occasionally by teleconference. Members are needed for the following committees: Audit, Finance, Outreach/Marketing and Technology. In addition sbaMass is beginning a Development Committee with the initial focus on a Walk and Roll for 2010. We are anticipating that the First Annual Walk and Roll will be the start of a great new fun awareness and fundraising event for sbaMass. If you have experience or interest in any of these areas, contact Ellen Heffernan-Dugan at edugan@sbaMass.org or 888-479-1900.



sbaMass 1st Annual Walk n' Roll

May 23rd, Endicott Estates, Dedham, MA

sbaMass is planning a Walk n' Roll for the Spring of 2010. The event will be held May 23rd at the Endicott Estates, Dedham, MA. Begin thinking about building your teams for what will be a great awareness and fundraising event.

If you are interested in volunteering to assist with the planning of this event, contact Ellen Heffernan Dugan at edugan@sbaMass.org or 888-479-1900. Volunteers are needed in a number of areas, corporate relations, day of logistics, planning committee. We look forward to you joining us for this fun family event!

Ask the Doctor

Question of the Month: Are people with Spina Bifida Occulta at an increased risk of osteoporosis? Are calcium supplements, such as Os-Cal, known or believed to be helpful for people with Spina Bifida?

We do know that both children and adults with repaired myelomeningocele have lower bone density in their lumbar spine and in their hips (greater trochanter) than the general population. This is true for both those who ambulate and those who use wheelchairs for the majority of their mobility. The decrease in bone density seems to be greater for those who do not ambulate, but may be due to other associated medical conditions rather than the lack of walking itself. The associated medical conditions that also impact bone density include kidney failure, use of anti-seizure medication, taking steroids for long periods of time, and associated genetic conditions such as Down syndrome.

There are no studies that I know of which show benefit from taking bone density medications in patients with repaired myelomeningocele. It is probably helpful to ensure adequate calcium and vitamin D intake. Adults should ingest 1500mg of calcium and 800 IU of vitamin D daily, particularly if they do not spend much time outdoors. If you are prone to kidney stones, you will want to talk with your health care provider before starting calcium or vitamin D supplements, as the risk of developing stones while on these supplements is not entirely agreed upon.

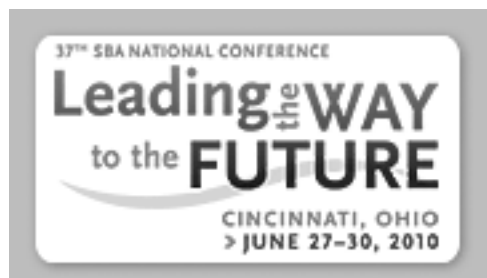
As for those with Spina Bifida occulta, there is less known. If there are no spinal cord issues, such as a tethered cord that interferes with the ability to ambulate, I don't think the bone density of the normally developed vertebrae should be decreased. The affected vertebrae that are not fused will be recorded as having a lower density because they are incompletely developed. Thus, I would suggest studying only to the fully fused vertebrae or the hip (greater trochanter) for the official measurement. As for those with myelomeningocele, calcium and vitamin D supplements should be helpful if there is insufficient intake in the diet.

Insights Into Spina Bifida Needs Your Stories

SBA's Insights Editorial Advisory Committee is currently looking for members of the Spina Bifida Community to feature for stories in Insights Into Spina Bifida, SBA's national magazine. Specifically we are interested in:

- Adults with Spina Bifida who have attended a trade or vocational school
- Adults with Spina Bifida who have participated in enrichment classes
- Adults and children with Spina Bifida who have interesting hobbies
- Parents of children with Spina Bifida who have successfully integrated their children into recess activities
- Parents of children with Spina Bifida with unique techniques for entertaining children after surgeries
- Parents of children with Spina Bifida who have tips on making marriage work in the face of the challenges of having a child with a disability

If you have stories meeting the above mentioned requirements, please contact Brenda Yablonsky, editor of Insights, at Brenda@yabcom.com.



Conference Scholarships for the Annual SBA Conference

Please join the Spina Bifida Association (SBA) for the 37th National Conference to be held at the Hyatt Regency Cincinnati (Cincinnati, Ohio) from June 27 - June 30, 2010.

Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians have the unique opportunity to gain information on the latest medical care and network on various issues which affect their lives and professions.

- Learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment, and much more!
- Attend practical workshops and special programming that address your own interest areas.
- Network with various interest groups - from others living with Spina Bifida to health professionals and product manufacturers.
- Find out how researchers are paving the way for more knowledge about Spina Bifida.
- Hear from leading Spina Bifida partners about the important role advocacy plays in our Community's success.

Updated sbaMass Conference Scholarship information is currently available on the sbaMass website: www.sbaMass.org. The due date for applications is: March 30, 2010. Contact Ellen Heffernan-Dugan at edugan@sbaMass.org or 888-479-1900 with questions.



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