Wisconsin's Alpha-1 Support Group Newsletter
all for 1 for all
THE ALPHA PACK NEWS
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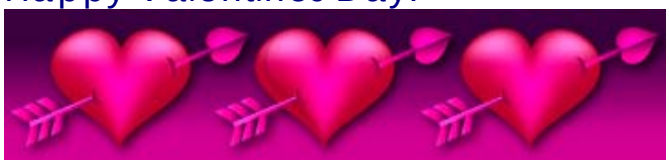
Happy Valentines Day!



Valentines Special on Kid's T-shirts

Give the gift of Alpha-1 awareness with an adorable child's t-shirt (designed by mother of two ZZ children, Jaime Freitag) and proceeds can help a Wisconsin family or individual affected by Alpha-1. And starting this Valentines Day, we are offering a 20% discount and free shipping on T-shirt orders placed between February 14-21, 2009. The white cotton t-shirts come in sizes ranging between 2T to X-Large 18/20. Choose between a boys or girls design. Specials are $12 for long sleeve and $10 for a short sleeve. Quantities are available until they run out. To view the designs, order online, or to print an order sheet, go to our web site www.thealphapack.org. Or contact Jaime at (262) 797-0620. Happy Valentine's Day!

Wisconsin Walks for Liver Disease

Grab your walking shoes and join the American Liver Foundation for the 2009 Liver Life Walk! Wisconsin has two walks planned: (1) in Milwaukee on August 8th at Veteran's Park and (2) in Madison on September 13th at Lake Farm Park. Registration is free, but walkers are encouraged to form teams and raise funds to support the ALF's mission. Raise $100 or more to receive the 2009 Liver Life Walk t-shirt. For the Milwaukee date, the Freitag family has formed the "2 Lucky Livers" team was for Alpha-1 awareness. You can visit, join, or donate to their team at http://tinyurl.com/alkpfp. Or, create your own Alpha-1 team by visiting http://go.liverfoundation.org or calling 1-888-945-4837. In addition to a walk, the morning will consist of food, festivities, and entertainment. Proceeds support research, education, and advocacy efforts to help the 30 million Americans currently living with liver disease.

Bowling in 2009 for TX Games in 2010

Are you an organ transplant recipient planning to enter the U.S. Transplant Games next year (2010) on July 30th through August 4th in Madison, Wisconsin? If so, this year's (2009) fourth annual Benter's Bowling Benefit on April 4th at Ruby Lanes in Two Rivers, WI is looking to help you. Mary Benter said, "100 percent of the proceeds will go towards supporting Wisconsin organ transplant recipients, donor families, and living donors attending the Transplant Games. Last year almost $4,000 was raised, and, this year, we are hoping to raise $6,000." She added that organizers are seeking bowling teams, silent auction items, and door prizes. For more information, to register a team, or to make a donation, contact Benter, (920) 772-4261 or e-mail BentersBenefit@yahoo.com. If you are an Alpha Pack member and want to create a team for a 2010 transplant game participant, contact Noreen at (920) 803-2668 or info@thealphapack.org. To find information on the U.S. Transplant Games, visit http://www.kidney.org/news/tgames/index.cfm.

Eliminate the 2 Year Medicare Wait

Those who are disabled and can no longer work can apply for SSDI; however, a problem can arise when people on disability insurance must wait 2 years to be eligible for Medicare. This seems incredibly inconvenient, especially when current medical costs continue to rise in this unstable economy. According to the article *ABOLISHING THE MEDICARE DISABILITY WAITING PERIOD* by Harold Pollack, "This waiting period goes back to 1972, when Congress expanded Medicare eligibility to include the disabled. Under current policy, people with disabilities must receive Social Security Disability Insurance (SSDI) for 24 months before becoming Medicare-eligible. Exceptions have been added for end-stage renal disease and ALS. Some states step in to fill the gap. Yet this policy imposes severe problems on many people." *Source: http://tinyurl.com/befurj*. Organizations across the U.S. are uniting to change the Medicare wait. In the Alpha-1 community, Miriam O'Day, Senior Director Public Policy for the Alpha-1 Foundation/Alpha-1 Association would like to hear from you. If you are willing to go public on this issue, please contact Miriam at 1 (800) 521-3025 or moday@alpha1.org and make your voice heard.

Central Fields Region Mtg. Minutes

by Dawn Smith, Support Group Co-Leader

The next Central Fields Region meeting will be May 7, 2009 at 3:00 p.m. For details, contact CFR Co-Leader, Dawn Smith, at (715) 536-8145 or CFRcoleader@thealphapack.org.

Green Bay Region Mtg. Minutes

by Noreen James, President and Director of Operations

The next meeting will be on Thursday, March 17th, Open Forum, weather pending. For details, contact Ron Bernard at (920) 490-7811 or GBRleader@thealphapack.org.

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Picture This!

Northern Lights Region Mtg. Minutes

by Judy Parker, Support Group Leader

The next Siren meeting will be "Latest lung medications and oxygen equipment" and is planned for May 21, 2009. For details, contact Judy Parker at (715) 653-2666 or NLRleader@thealphapack.org.

Southern Shores Region Mtg. Minutes

by Noreen James, President and Director of Operations

Milwaukee's January meeting invited Jill Simaras, Lung Transplant Coordinator for Froedtert & Medical College. Jill spoke on the lung transplant evaluation process. For Alphas considering transplant, they learned that the UNOS allocation system takes into account the severity of a condition. To determine this, a patient undergoes a series of tests by a team of doctors at a transplant center. Once completed, the higher the allocation score is the higher the placement on the transplant list. The UNOS system works well, but it does not guarantee that a patient will be transplanted soon. Many factors such as a blood type, body size, location, and diagnosis can slow the process down. To assure a smooth flow, the Transplant Coordinator's job is 24/7. They are the patient's main connection to the team of doctors once the process begins.

A Transplant Coordinator will have a patient's number on speed dial should the right lungs come about. Same goes for the patient. For example, while waiting on the list, problems such as illnesses or exacerbations need to be reported to the coordinator right away. This is to assure that the transplant process stays on track and not halted by a roadblock such as an infection or virus. Thus, in conclusion, patients need to stay connected with the coordinator pre and post transplant. The entire presentation was wonderful. Jill helped to make the UNOS system quite easy to understand and she spoke to an attentive audience of 19 people. Talecris, the manufacturers of Prolastin® www.prolastin.com hosted food and refreshments. Thank you to everyone who could attend that evening! The next meeting will be on Thursday, March 12th, Open Forum, weather pending.

Caregiver Teleconference

by Jaime Freitag, Liver Aide

The National Family Caregivers Association (NFCA) provided a "Health Advocacy Training for Family Caregivers." It was a 2-part series held on November 8th & 13th, 2008 to help family members be better advocates by effectively communicating with healthcare professionals when providing care for a friend or loved one. The presenter was Crystal Dea Moore, an associate professor and director of a social work program at Skidmore College; a John A. Hartford Foundation Scholar in geriatric social work; and a master trainer in communicating effectively. I noted some valuable information as to how you can be an effective caregiver. All of this information and more can be viewed on two PowerPoint presentations at: http://www.telspan.com/attachments/nfca/NFCAppt.pdf and http://www.telspan.com/attachments/nfca/NFCApart2.pdf

There are benefits and challenges of the healthcare system that a caregiver will experience. To reap the benefits of enhancing life, you encounter many challenges such as confusion, medical terminology, no priorities, or patient value. You must "Establish Your Presence" by physically meeting with the healthcare professional(s) and establishing your rapport with heart and mind. Show your "Active Participation" by organizing all necessary information and preparing for each visit by focusing on important issues. Present "Assertiveness" by providing feedback, asking for clarification, recommending solutions and asking the professional for further explanation to fully understand. It is important to implement all these steps to provide the proper care.

As a caregiver, there is so much to know about the person you are caring for- managing their chronic illness, nurse visits, insurance/reimbursement, doctors, their personal communication strategies with specialists/healthcare professionals, and keeping everything in order. Since you are the most important link between the friend/loved one and the healthcare professional it is crucial that you have all the necessary information. Compiling all the information is the first important step. Next, write in an objective manner on behalf of the patient's best interest. Finally, request a copy of everything, especially labs/blood work. Do not wait for the doctor to call you if there is a problem; review the reports yourself and make notes to ask questions.