



Alphas Alike or Different Survey Results

By Jaime JS Freitag

Did you ever wonder what traits you share with other Alphas or Alpha-1 carriers? What similarities do he and I share or what differences have he and I experienced throughout our Alpha-1 journeys? The Alpha Pack created their first survey and the results are in! From April 1st thru July 1st, 2010 we had paper copies available & online access thru Survey Monkey. Online, 55 surveys were started, with 51 totally completed a, 92.7% completion rate. The information consisted of personal, spousal (or significant other) and child/children's information regarding their Alpha-1 or carrier status. Any new members joining will be asked to complete a survey and results will be updated annually. All surveys were taken confidentially and anonymously; no names or contact information was requested. The survey's sole purpose was to only gather data to share with Alpha Pack members and other interested parties.

As for the results, they were very interesting and some were even surprising! If you have any questions or would like additional information please do not hesitate to email Jaime JS Freitag at myalphashunterandmia@yahoo.com. Here are some survey results highlights:

- ~ 74% of our respondents have Alpha-1, which includes 61.8% lung-related, 7.3% liver-related and 3.6% skin-related.
- ~ 27.3% of respondents are Alpha-1 carriers.
- ~ 2009 was the most popular year to get tested for Alpha-1/carrier. 2002 came in a close second and 2008, 2006 and 2000 tied for third. The earliest date a respondent was tested was 1978.
- ~ The most common age range to get tested for Alpha-1/carrier was 51-60 years old, with 31-40 and 41-50 being the next popular age ranges.
- ~ Of the primary respondents, 1% of their spouses/significant others have Alpha-1 and 13% are carriers.
- ~ The most common age range for spouses/significant others to get tested for Alpha-1/carrier was 61-70, with 31-40 coming in second and 51-60 coming in third.
- ~ 72.2% of our respondents have between 1 and 7 children, with 2 being the most common number (27.8%) of children.
- ~ Of those 27.8% children, 11.1% of them have Alpha-1 and 18.5% are Alpha-1 carriers.
- ~ 5.6% of respondents with Alpha-1 had transplants; 2 were lungs (1 single & 1 double) and 1 was a liver transplant and all were on the waiting list between 4 and 10 months before being transplanted.
- ~ 66.6% of respondents knew of a family member that had lung, liver and/or skin issues before being diagnosed with Alpha-1/carrier.
- ~ 56.8% of respondents had lung/liver/skin conditions before diagnosed with Alpha-1/carrier.
- ~ 58.8% of respondents have smoked and 1 pack was the average amount smoked per day. 19% of the respondents, 14% of their spouses/significant others and 4.1% of their children quit smoking before diagnosed with Alpha-1/carrier. Of those

5.9% of respondents, 4% of spouses/significant others and 10.2% of children have not quit smoking despite their Alpha-1 diagnosis.

~ 83.7% of respondents, 86.7% of spouses/significant others and 93% of children consume alcohol daily.

~ 56% of respondents, 10% of spouses/significant others and 24.5% of children have not quit drinking despite their Alpha-1 diagnosis.

We thank everyone for their participation and hope this may help answer some of your questions.



Wisconsin Alpha Pack members enjoying the A1A conference!

A1A Conference Review

Disney World brought over 600 attendees and 30+ little Alphas & their families, including the youngest attendee at 5 months old and the eldest at 82 years old. This year's National Conference focused on many different issues that affect Alphas in various perspectives. From Family Awareness to Alpha-1 & Children to Health Care Reform each session had a center focal point- living with Alpha-1. Professionals from across the US presented 12 breakout sessions, including Nutrition, Children's Alpha-1 Lung & Liver Health, Transplantation, Augmentation Therapy and Oxygen; all highlighted how important education is in order to live a healthier, Alpha-1 lifestyle. Next year, June 10-12th, 2011 will mark the 20th anniversary of the National Education Conference. The Conference will be at the original location- St. Paul, MN. More information is to follow about St. Paul, MN in 2011. If you would like to download or view this year's conference presentations online, please visit <http://www.alpha1.org/education/10natconf.php>

BioLife Tour- Sheboygan

A tour of Baxter's BioLife facility in Sheboygan is scheduled for Thursday July 29th at 10am. Learn how BioLife collects high quality plasma from donors and how it is processed into life-saving plasma-based therapies. Lunch will follow the tour. Since only a limited number of people can be allowed in a tour, please contact our office to sign up. The tour will close once it is full (10 people). To sign up, contact Noreen at 920-803-2668 or info@thealphapack.org for details.

Changes in We Care



Pick N Save is currently changing its *Advantage Plus Savers Club Card* and asks for all those carrying one to update their card and re-designate their

charity of choice in which a % from the grocery bill will go towards them. To select the Alpha Pack as your charity, please go to any Pick 'n Save service desk and request an update on your Club Card. The Alpha Pack is a listed charity through Pick 'n Save's **We Care** program. Our charity code is 023225.

Southern Shores Region Mtg Minutes

Our last meeting welcomed Diane Baughn of the Alzheimer's Association (SE WI Chapter). Baughn gave us insight on brain health and the warning signs of dementia. The Alzheimer's Association's mission is to provide a warm knowledgeable voice on the phone, accurate information, face-to-face consultation and support, specialized educational opportunities, and the safe return of a loved one. There is a 24/7 phone Helpline 800-272-3900, as well as Alzheimer's facts and figures at www.alz.org. Baxter, the manufacturer for Aralast@ www.alpha1health.com, hosted food and refreshments. Southern Shores Region's next meeting will be on Thurs., Sept 9th from 6:30-9 PM. For details, please contact Jaime Freitag at (262) 797-0620 southernshores@thealphapack.org

NOTE! In our last issue we neglected to thank CSL Behring, the manufacturers for Zemaira@ www.zemaira.com for hosting the food and refreshments for Southern Shores, April 8th meeting. Our apologies and thank you!

Central Fields Region Mtg Minutes

Central Fields Region's next Alpha-1 meeting will be held at Marshfield Clinic, East Wing, LL Room 4, on Thurs., Sept 2nd 2010 from 3-7 PM. For details or to RSVP, contact (920) 803-2668 or info@thealphapack.org

Northern Lights Region Mtg Minutes

The last meeting on May 20th was an *open forum* for members to meet and talk. Thank you goes out to CSL Behring, the manufacturers of Zemaira@ www.zemaira.com for hosting the food and refreshments from the Chattering Squirrel. The next meeting will be held at the Burnett County Government Center (Siren, WI) on Thurs., July 15th, 2010 from 6-9 PM. For details or to RSVP, contact Judy Parker at (715) 653-2666 or northernlights@thealphapack.org

Green Bay Region Mtg Minutes

The last meeting on May 18th was on *O2 Therapy Updates* presented by Apria. Thank you to CSL Behring, the manufacturers of Zemaira@ www.zemaira.com for hosting the food and refreshments. Green Bay Region's next meeting will be on Tues., July 20th at Aurora BayCare, Sports Med Center (Endeavor Room) 1160 Kepler Drive, Green Bay, WI 54311 from 6:30-8:30 PM. Topic will be on *Wisconsin Assistance Programs* (including WI Phone Relay System, ICS Energy Assistance, and Unclaimed Property Outreach Tour). For details or to RSVP, contact (920) 803-2668 or info@thealphapack.org

Transplant Games in Madison, WI

The 2010 **National Kidney Foundation U.S. Transplant Games** is a four-day athletic competition (**July 30-August 4 in Madison**) open to all recipients of life-sustaining solid organ transplants, including heart, liver, kidney, lung, pancreas and bone marrow/stem cell transplants. The Games promote the success of transplantation and call attention to the need for more donors. To visit the Games website, please go to www.transplantgames.org.

Irene's Tombstone

Thank you to the local community and Alpha Pack members who donated a total of \$2500 towards Irene Lang's tombstone. It is on order and will be placed at her family gravesite in Arlington Cemetery (Milwaukee) by this summer. Because of your help, Irene can honorably rest in peace.

Got Alpha? Get Tested!

With the help of local physicians, Wisconsin's Alpha Pack now offers confidential and free testing for the genetic condition Alpha-1 Antitrypsin Deficiency by becoming a point-of-service screening site. The test results remain private unless you choose to share it with your family physician. If you are interested in being tested for Alpha-1 or if you would like the Alpha Pack to screen at your health fair, please contact us at 920-803-2668 or info@thealphapack.org. Results take about one month to return.

ALF Liver Life Walk 2010



The annual Liver Life Walk still needs more walkers for Alpha-1. Walk with an existing team or create your own. We currently have 2 teams for Alpha-1 awareness- **2LuckyLivers** (Milwaukee) and **PiperPower** (Madison). Teams walking for Alpha-1 will receive Alpha Pack t-shirts to keep. The Milwaukee walk will be on Saturday, August 7th at Veteran's Park at the lakefront. The Madison walk will be on Saturday, August 28th at Lake Farm Park. Registrants can walk or run on 3 different paths available (up to 5K). Following the walk is a reception with free food to all participants. Participants who raise \$100.00 for the American Liver Foundation will receive a Liver Life Walk t-shirt and other prizes for higher amounts raised. To register your team today or to participate in the walk, please visit: www.liverfoundation.org/chapters/wisconsin and click on Milwaukee or Madison. Contact Jaime Freitag (262) 797-0620 or myalphahunterandmia@yahoo.com for more information.

Volunteering

The Alpha Pack is a listed agency with the Volunteer Center for Milwaukee. People who wish to give back to the community or gain hours, can look for opportunities and sign up. Anyone can volunteer. We are currently looking for individuals to help at events across Wisconsin where we will be offering Alpha-1 screenings to the public. We also need nurses willing to volunteer their time at these events to perform finger sticks for the collection of blood samples. Sign up is easy! If interested, visit <http://volunteermilwaukee.org> or contact our main office.