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SO CAL ALPHAS

Support group



Southern California Alphas started the New Year with a support group meeting at Kaiser Permanente medical center in Woodland Hills. Highlights included Alphas and

Industry people attending for the first time and special guests Marlene Erven and Dr. Rajat Walia.

Ms. Erven presented an overview of the Alpha-1

Association whose mission is to identify individuals affected by Alpha-1 and improve the quality of their lives through Support, Education and Advocacy and to encourage participation in Research.

As Executive Director for the Association, Ms. Erven has been a driving force in implementing programs to support that mission. She also directs the Association's collaboration efforts with the alpha-1 Foundation whose mission is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency.

Activities of Support include over 70 Support groups and National Support programs. The purpose of the Support groups is to provide support and education to Alphas and family members, create awareness in the community and advocate for national and state issues that affect Alphas.

There are also virtual support groups for Alpha-1 families, Caregivers and patients involved in pre and post transplant.

Other programs include the Patient Information Hotline 1-800-245-6809, Peer Guide program 1-877-346-3212, Genetic Counseling Call Center 1-800-785-3177.

In addition, more information can be found on the Association website at www.alpha-1.org.

Dr. Walia, the assistant director of the cardiothoracic transplant center at St. Joseph's Hospital located in Phoenix, AZ, began his presentation by saying that St. Joe's has now performed 34 lung transplants and became Medicare certified in September 2009.

He went on to speak about the care and maintenance of Alpha patients so that they would not reach the point of needing a transplant.

At the top of his list was exercise. He pointed out that all of the muscles in the body use oxygen and by being in better condition they can use it much more efficiently. Along with that he made note of diet. Many of us eat too much and often we don't eat enough of the right things that make up a balanced diet. The Doctor also touched on the state of research and where he thinks it will lead. He has previously worked with Dr. Brantly in

Florida. While he didn't spend too much time on transplant, it was one of a number of subjects he touched upon during an very informative question and answer session.

Everyone in attendance felt they had gotten much in the way of practical knowledge that they could take with them.

ALPHA-1 ASSOCIATION SCHOLARSHIPS

The Alpha-1 Association has announced that they will be making a total of 7 scholarships available annually to Alphas and their immediate family who demonstrate financial need and who have been accepted for study at an approved institution such as an accredited university, community college or technical institute. Funds can be used for tuition, registration and other fees and books and related materials. For more information go to the Association website or call Louise Koonce at 1-800-521-3035, ext. 16 or email her at lkoonce@alpha1.org.

NATIONAL EDUCATION CONFERENCE

The Alpha-1 Association will be holding their 19th National

Education Conference June 11-13, 2010 in Orland, Florida.

The theme for this years Conference is "Unlocking The Family Genes: The Key To A Healthier Life".

By attending the Conference you can expand your knowledge of Alpha-1, meet the experts in Alpha-1 related liver and lung disease and transplantation and connect with the Alpha-1 Community and see how you can make a difference!

HOW TO MAKE THE ALPHA-1 WORLD A BETTER PLACE

1. Attend Support Group meetings.
2. Support the work of the Alpha-1 Association by becoming a member.
3. Support the work of the Alpha-1 Foundation by making a charitable contribution.
4. Educate your family about Alpha-1.
5. Create Alpha-1 awareness in your community.
6. Create Alpha-1 awareness in your medical community.
7. Join in Alpha-1 Advocacy efforts.
8. Volunteer for research.

And most importantly:
Take care of your self.