Leading Vision Group supports International Rare Disease Day 2009

Leading Vision group Retina International has announced its support of the second annual International Rare Disease Day which will take place on Saturday February 28 2009. The day will be celebrated with many diverse events designed to provide information on this important subject across Europe, The United States and Latin America.

The purpose of International Rare Disease Day is to raise awareness of rare diseases and of their impact on the lives of those affected, their families and society as a whole. It is hoped the day will reinforce the importance rare diseases as a public health priority. The event is organised by members of the European Rare Diseases Organisation (EURORDIS) and its international partners.

Retina International is an umbrella group of 33 national societies promoting research and providing information on rare degenerative eye conditions including, Retinitis Pigmentosa (RP), Usher Syndrome, Leber's Congenital Amaurosis (LCA) and Stargardt's disease as well as other allied rare retinal dystrophies. One of the key priorities of Retina International is to foster cooperation between international scientific and patient groups to ensure all the elements are in place to facilitate the development of therapies for rare retinal diseases.

President of Retina International Ms. Christina Fasser said 'It is vital that we continue to raise awareness of chronically debilitating diseases that although considered rare, when viewed internationally can affect millions of adults and children. To facilitate therapeutic development for rare disease it is essential for us to work internationally'. She added '2008 saw great results in two gene therapy trials for a rare retinal disease called Lebers Congenital Amourosis (LCA) both in the UK and USA. Here a small group of young patients had some partial sight restored. To take these trials to the next level a greater number of patients with the same condition will need to be indentified. Access by scientists and clinicians to properly funded well resourced and internationally coordinated patient registries can speed up this process and, it is hoped, will bring about a cure for rare blinding conditions at the earliest opportunity'.

In many countries the needs of patients with rare eye conditions are not being met as there are often barriers to accurate diagnosis and where possible appropriate intervention. Retina International is showing its support by

encouraging members all over the world to support local activities on February 286h, 2009.

Mr. Yann Le Cam CEO of Eurordis said ‘As a direct result of the attention we expect Rare Disease Day 2009 will raise, we hope national healthcare systems improve the availability and quality of diagnosis, treatment and care for rare disease patients throughout Europe and the world”.

Rare diseases are chronic, progressive, degenerative, and often life-threatening with high levels of pain. There is no cure today for the 6000 - 8,000 rare diseases, 75% of which affect children.

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