

## Torbay Alstrom charity founder dedicates international accolade to her children



Saturday, March 02, 2013

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INSPIRATIONAL Torbay charity Alström Syndrome UK has won an international accolade to mark its pioneering work in Europe.

The Paignton-based charity was set up in a front room in Southfield Avenue by a mum who lost both her children to the rare disease.



Award: Kay Parkinson with Avril Daly, vice chairman of EURORDIS.

Kay Parkinson received the award at a special gala dinner in Brussels and dedicated it to her children Matthew and Charlotte.

Alström Syndrome is a very rare inherited condition, which affects the body's metabolism with particular impact on all major organs including the heart, lungs, kidneys and liver.

The heart becomes weakened and enlarged and often leads to premature death. Kidney failure may also occur.

During childhood, patients suffer deteriorating eyesight, often leading to blindness. Hearing loss and Type 2 diabetes are also common.

Charity and founder and chief executive Kay said: "Children now diagnosed will have increased life expectancy and their quality of life will be improved dramatically.

"We learned from what happened to mine and try to make sure that same horror story isn't replicated time and time again. For my children, it really was a horror story.

"It doesn't make me angry, it just makes me sad that people with very rare diseases have been forgotten in the system and still are.

"Rare Diseases Day is held in Britain this week to draw attention to the fact that one in 17 people are affected by a rare disease — that's more than are affected by cancer cumulatively, but because each individual disease is rare, they do not get the publicity."

Now thanks to the Parkinson's charity, children all over Europe are being diagnosed and treated earlier, saving many lives.

Kay said: "This is a great honour. It also strengthens our resolve to keep on fighting to gain more recognition for rare diseases in Europe and around the world."

The award for patient care was given by EURORDIS, the European Organisation for Rare Diseases, a non-governmental alliance of patient organisations and individuals dedicated to improving the quality of life for people living with rare diseases in Europe.

The award was presented on February 26 at the second Eurordis Black Pearl Gala Dinner.

Kay has also now been instrumental in setting up Alström Europe and has been given the honour of being the first president. Thirteen countries are now signed up.

Fwd: Iyi-ACHSE - Ms Köhler's award

Sukzes-Paid Iyi-ACHSE - Ms Köhler's award  
From: Sharon Köhler <sharon.koehler@achse.org>  
Date: 03/20/2013 10:49 AM  
To: Karen Healy <karenhealy@achse.org>

Hi,

Ms Köhler's award was presented to her by the gala committee.

Thank you  
Sharon

----- Original Message -----

Subject: Iyi-ACHSE - Ms Köhler's award  
Date: Wed, 20 Mar 2013 10:43:26 EDT  
From: Sharon Köhler <sharon.koehler@achse.org>  
To: Karen Healy <karenhealy@achse.org>, Sharon Köhler <sharon.koehler@achse.org>

