May 2016

For the attention of the head teacher;

I have pleasure introducing you to the Ichthyosis Support Group (ISG). The group was formed to provide support and assistance to individuals and families having to deal with this rare and distressing condition. The reason for contacting you at this time is to seek the school’s support in helping us to promote the Ichthyosis Awareness Month of May and hopefully assist in our fundraising efforts.

What is ichthyosis?
Ichthyosis, pronounced Ick-thee-o-sis (which comes from the Greek word meaning ‘fish’) describes a group of conditions in which the skin is dry and scaly. Lots of people have dry skin conditions (such as eczema or psoriasis) but they tend to be patchy and they come and go. By contrast, in ichthyosis the scaling is continuous and usually affects the whole body. Most types are congenital, meaning that they are present at birth, and inherited, meaning that they result from genetic changes, so they may run in families. There are many different types of ichthyosis.

The ISG is a support network which exists to help people with the condition by providing opportunities to meet other families and individuals with the condition to share experiences, and exchange hints and tips for managing the condition.

SUPPORTING the ISG
The person handing you this letter will in some way have a connection with the condition. It could be they are a parent who has a child at the school with the condition or they could be a parent with the condition themselves. Whatever their link with ichthyosis they are seeking to support the ISG and would like you to consider allowing the school to help in that support. The ISG has to generate the funds to finance everything it does. This is done by applying for grants, receiving sponsorship from pharmaceutical companies, but by far the biggest contributor to our income is that generated by fundraising initiatives.

During Ichthyosis Awareness Month we encourage our members to do various fundraising challenges, one of those challenges is the Ichthycyclotron. If you were supportive we believe a School’s Ichthycyclotron would be a tremendous way of involving the school and the children in helping to raise funds for the group. In order for schools to participate in this we are asking if the children could ride for one mile 1.9 kilometres (which is just over a mile) around the school grounds. They could ask family and friends for sponsorship perhaps based on the number of ‘laps’ they achieve. We are suggesting 1.9 kilometres as the group is 19 years old this year!

The child raising the most money would be entered into our young fundraiser of the year award, and the school would be recognized through all of our media outlets.

I do hope you are able to lend your support to this initiative. It is a fantastic way of involving both the children and the school in a community project which will in turn give much needed support to an excellent cause. For more information please contact us at the details above.

Thanking you in anticipation

Paul W Whitehouse
ISG Chairman
Ichthyosis Support Group