

# SOUTHEND CYSTIC FIBROSIS ASSOCIATION

## REG CHARITY NUMBER 1101805

Cystic fibrosis ( CF ) is the UK's most common, life-threatening, inherited disease. It affects vital organs in the body, especially the lungs and pancreas, clogging them with thick, sticky mucus. The lungs become progressively more damaged by bacterial infections as a result of this mucus clogging. There is no cure for cystic fibrosis, and approximately half of those affected will die whilst still in their teens.

Treatment is aimed at preventing the build up of mucus to slow the progression of the disease and is an arduous, time-consuming daily routine. Chest physio is performed at least twice daily, every single day, followed by nebulised drugs to treat bacterial colonization of the lungs and other nebulised drugs to help airways clearance. All food and snacks have to be accompanied by enzyme capsules, without which food cannot be digested. Most CF patients take around 50 plus tablets a day of various types.

Apart from the time consuming daily treatment, CF patients have frequent hospital visits, including courses of intravenous antibiotics ( these are often done in the home setting). Fitting ordinary daily activities such as study or play around treatment schedules can be difficult for the CF child, and the strain on the family as a whole (particularly any non-CF brothers or sisters) can be considerable.

The Southend Cystic Fibrosis Association aims to provide equipment and services to improve the quality of life of those with CF in the Southend area. We are a registered charity (details can be found on the Charities Commission website) and we are reliant on fundraising events and individual donations, as we receive no Government funding.

Running costs of the charity are nil as the committee are all volunteers, many of them being CF parents. Even the cost of stamps is borne by the committee.

Examples of what we provide are nebulisers, in-flight oxygen, trampolines and exercise equipment or classes/gym membership to improve fitness, portable oxygen condensers to enable some otherwise housebound young people the freedom to go out, and prescription payments. We provide individual lung function machines and oxygen monitors for home use to our older patients, to enable the specialist centres in London to assess certain readings via the telephone and advise accordingly, and we pay travel costs incurred for each journey to a London CF centre – this has proved to be a valuable way of ensuring patients are able to access the specialist care they require, as often as necessary, without the added burden of the financial cost of the journeys. In addition, we occasionally provide equipment to the Hospitals where our patients are treated, both medical (where that equipment directly enhances the care received by our patients and would not have been otherwise available on the NHS) and recreational, such as the provision of Wii fit equipment for the CF wards our patients use – these have proved particularly popular! We also make a grant available towards the additional costs incurred during hospital admissions - admissions can be lengthy and frequent and can prove very costly to the already stretched family budget. We have a ringfenced fund within the charity called the Hannah's Happy Days Fund, which makes an allowance to the CF individual each year so that they can plan something fun to look forward to, such as a day out, a weekend away, tickets to see a show - it is important to have something to look forward to amid the daily treatment burden that CF places on the sufferer and their family.

