



The Fighting Irish - win another round to improve CF Care

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Ireland is a small island country on the Western Atlantic seaboard. The island of Ireland is divided in two, the Republic of Ireland and Northern Ireland (part of the United Kingdom). The Republic of Ireland has a population of 4.3 million and is unique in that the country has the highest incidence of CF in the world per head of population as reported by the World Health Organisation where 1 in 19 people carry the recessive gene that causes CF. As well as having the highest incidence of CF in the world, Ireland also has a very high prevalence of the most severe CF mutations.

Historically, the Irish CF population has been a sick population with low mortality rates compared to other developed countries. This was due to two reasons 1) the lack of sufficient facilities and multi disciplinary CF medical teams, and 2) the genetic profile of the Irish CF population. In spite of Ireland's high incidence of CF in the country it is still an orphan disease with relatively small patient numbers compared to cancer for example. As a result CF was not recognised or known about by the public at large and was not seen as a priority by the health authorities. CF however is recognised by the State as a long term illness and all people with CF (PWCF) are entitled to free hospital care in state hospitals; free prescribed medications including certain high tech drugs; and various social welfare payments (some that being means tested).

The Cystic Fibrosis Association of Ireland believed that Ireland had fallen behind when it came to modern CF care (including appropriate hospital facilities and staffing levels) and that it needed to highlight this fact to the government and the general public at large. The Association felt that the only way to do this was to commission a report by a recognised independent expert that could be presented to government, the health authorities, and to the media and general public. This report had to be factual and to stand up to in depth cross examination by the health authorities.

The report entitled "The Treatment of Cystic Fibrosis in Ireland: Problems and Solutions 2005" was published in February 2005 and made a number of key recommendations for the future development of CF services in Ireland. (A copy of this report is available on the CFAI website – www.cfireland.ie .) This report highlighted that:

- Urgent action needed to be initiated to correct the dangerously inadequate specialist staffing levels in hospitals providing CF care
- Fully supported CF Centres needed to be designated that allow reasonable geographic access and provide access to proficient multi-disciplinary teams
- All beds for cystic fibrosis patients should be in single rooms with ensuite toilet facilities to prevent the transmission of dangerous organisms
- A consultant microbiology services should be available at each CF centre
- A Microbiology Reference Laboratory should be established to support and inform all regional centres and champion advances in knowledge and treatment
- A neonatal screening programme should be established for CF
- A CF Registry of Irish patients needed to be adequately funded and developed



This report, known locally as the Pollock Report after its author Dr. R. Pollock was used as the foundation of a very active lobby campaign that is still on going three years later.

The campaign to date has delivered the following:

February 2005	€300,000 in emergency funding for the National Adult CF Centre
November 2005	Government allocated €4.78m in additional annual recurring funding for new CF hospital based positions to commence in 2006 – this equated to the equivalent of 56 additional multi disciplinary medical posts in CF centres across the country
November 2006	Government allocated an additional €2m in annual recurring funding for new CF hospital positions to commence in 2007 – this in theory was to increase the total new medical posts between the two years to approximately 80
May 2008	Funding received for CF Registry allowing it to operate as a stand alone entity from the Cystic Fibrosis Association of Ireland
August 2008	8 single ensuite rooms commissioned at the National Adult CF Referral Centre as an interim measure while a new CF unit consisting of approximately 34 single rooms is being constructed – to be completed by the end of 2010

The above achievements have not come about just as a result of publishing an independent report on facilities and services for CF in Ireland. The report acted as the foundation and as a catalyst for a CF awareness campaign that will continue to evolve into the future. While the above achievements are considerable they can appear better than what they are, there have been huge frustrations, delays and logjams along the way but we cannot falter towards our goal of developing Ireland into an international centre of excellence for CF care.

Our awareness campaigns have been hugely successful. Four years ago very few people knew about cystic fibrosis, now politicians, the media and general public are very aware of this life threatening disease. The profile for CF and for our Association has increased exponentially and this can be substantiated by the coverage we have received in the media (including prime time television) and by the various awards that the Association and our members have received, these include person of the year awards in various regions, finalist in the Irish Healthcare Innovation Awards 2008, winner of the Public Relations Institute of Ireland's Award for Excellence in Public Relations 2008, and a PWCF winning Young Person of the Year Award that was broadcast live on national TV. The main benefit from the increase in awareness has been an increased acceptance and enthusiasm to fundraise for CF projects. The CF community is now successfully fundraising to provide additional adult and paediatric facilities and services across the country that will include a National Microbiology CF Reference Laboratory.

While the Irish campaign has been successful in Ireland it may not be directly transposable to other countries. What can be learnt from this success story is before you begin a campaign, know your facts and be able to substantiate those facts from a reliable independent source. Know what goals you want to achieve both in the short and long term. If you want commitment from the government make it simple to understand, quantify your requirements and be able to say how much these will cost. Identify any long term cost savings that could come as a result of an upfront investment. Identify key spokespersons affected by CF who are prepared to tell their



story. Make sure the story has a common thread and appeals to the media. Initially you will find very few people will be prepared to talk publicly but as the momentum picks up more will come forward. Don't accept rejection and don't expect immediate results. Be tough and forceful in your negotiations but be fair. Don't lose focus of your goals but re-evaluate them on a regular basis to make sure that they are still relevant.

As Ireland has the highest incidence of CF in the world we will continue to strive towards becoming a leader in the provision of CF care and facilities. Our journey has only just begun, we have a long way to travel and there will be many obstacles and frustrations in our way before we reach our journey's end. CF is an international community and a family. Ireland has learnt a lot and has received moral support by being part of this international community. We wish you every success in your individual efforts to improve the quality and quantity of life of those affected by cystic fibrosis.