



News Update

**Cystic Fibrosis
Association of Ireland**

Summer
May 2008

Introduction

The Association has had huge challenges over the last four years. Cystic Fibrosis is an orphan disease i.e. it has a relatively small number of people effected by the disease as a percentage of the total population of the country. In 2005 when the Pollock Report was published very few of the general population were aware of cystic fibrosis. We can safely state that this is no longer the case and we have succeeded in dramatically increasing the profile and awareness of cystic fibrosis not just to the general public but to the government and members of all political parties.

Our standing as a leading Patient Association and as a powerful advocacy group cannot be denied. This fact needs to be maintained and developed further. We are now finally seeing the fruits of our various campaigns. Multi disciplinary medical teams are now being rolled out across the country. The pace at which this has been happening is unacceptably slow but we are doing everything possible to identify log jams and free them up. The provision of adequate medical facilities across the country have been identified as an urgent priority. In this news update we will give an update as to what is happening in the main CF centres around the country.

Resources at CF House are limited and we have a dedicated team of people who work tirelessly to provide services to our members, to promote awareness, to generate funding, and to fight for the rights of PWCF. Communication has been identified as an area that needs to be improved and we will do our best to improve this by getting regular news updates out to all our members. We must all recognise that communication is a two way process and can I encourage everyone to participate in branch activities and for branches to communicate back to National Office their requirements, concerns and activities.

Inside this issue:

<i>Branches Concerned About Control of Accounts</i>	1
<i>Two CF Lung Transplants in April</i>	2
<i>Annual Conference & AGM</i>	2
<i>Medical Facilities Update</i>	2-4
<i>CF Working Group</i>	4
<i>Research</i>	5
<i>CF Registry</i>	5
<i>Tax Relief on Medical Expenses</i>	6
<i>Irish Hospital Innovation Awards 2008</i>	7
<i>CFRI Comments</i>	7
<i>Hypertonic Saline</i>	7
<i>CFAI Board</i>	8

Branches Concerned About Control Of Accounts

At the AGM of the Association held on the 12th April in Drogheda it became apparent that members still do not understand why branches are being asked to open new bank accounts in the name of the Association and who will control these accounts in the future.

Last year the Association changed its legal status from a Voluntary Organisation to a Company limited by guarantee. The reason why this change took place was to prepare the Association for compliance with new Charity Legislation that will shortly be introduced. Previously when the accounts of the Association were audited branch accounts were not taken into consideration and a statement to that effect was always included in the Auditor's Report. Company status brings increased reporting responsibility and transparency in all financial activities of the Association including branch funds. This is a legal requirement and is not National Office trying to control branch funds.

What process has to be followed?

All branch treasurers have

already been sent instructions on the completion of new bank mandates but very few have been received back. Each branch has to fill in who their signatories are going to be on their account and to return the mandate to National Office to be signed by the National Chairperson who authorises on behalf of the company the opening of an account. It must be stressed here that while the National Chairperson signs the mandate he is not a signatory on the branch account. The only authorised signatories are those stipulated by the branch and as a result the branch continues to control how branch funds are spent. National Office submits the completed mandate to the bank as well as the internet banking forms. Upon receipt of new cheque books National Office will forward these immediately to the branch treasurer.

Once the new account is open each branch will transfer the contents of the old bank account into the new account and close the old account. It is important to do this as the Cystic Fibrosis Association of Ireland (a voluntary organisation) no longer exists and has been replaced by the Irish National Cystic Fibrosis Association of Ireland, a company limited by guarantee with no share equity, trading as the Cystic Fibrosis Association of Ireland.

Every month branch accounts will be balanced and reconciled and copies of income and expense receipts will be sent to the Association's bookkeeper at National Office.

Who controls the branch accounts?

The branch controls the branch account via its branch treasurer.

What can the branch spend branch funds on and is there a limit on branch balances and on spending authorisation?

Branches have total autonomy on how they wish to spend locally raised funds. Branches themselves gave feedback at a recent National Executive meeting as to the maximum amount that a branch should hold in its account, which was approximately €11,000 excluding any special project account that has been approved by National Executive (now the Board of Directors). The amount retained in a branch account is not a ruling but was agreed by consensus of opinion. Branches do not require authorisation or approval from National Executive as to how or on what local funds are spent on as long as there is an audit trail for all transactions and are within the spirit of caring for PWCF and their families.



Branch Accounts continued from page 1

Why is it important that we declare all branch income as we did not do it before?

Firstly it is a legal requirement for the Association as a company.

Secondly it makes the activities of the Association totally transparent and auditable.

Thirdly it will boost the total income reported in our Annual Financial Statements and truly reflect the size of the organisation.

Fourthly the Charity Status and Charity Number have now moved from the old Association to the new Company and any funds not

covered by the charity number are taxable.

Fifthly the Revenue Commission is carrying out spot checks on companies who are claiming tax exemption on charitable donations. The Association has to be in a position to substantiate that these donations did take place. This was stressed at the AGM by our auditors.

Sixthly the Association can apply to the Revenue Commission for tax rebates on any private donation in excess of €250 made during any one tax year.

Three CF Double Lung Transplants in 2008

Two double lung transplants on Irish CF patients took place at The Freeman Hospital, Newcastle in April and one in May so far. This is excellent news and we are informed that both patients are making good progress. The Association is very concerned with the low number of transplants as only two transplants on Irish CF patients has taken place for the calendar year so far. The Association's transplant committee had a meeting scheduled for 9th May with all interested parties involved in CF transplants. It is very difficult to establish a date suitable to all participants and now the

meeting for the 9th has been cancelled as one important participant was forced to cancel. We are now trying to arrange a revised meeting date. We are continuing to gather information on how other countries optimise lung transplants and organ recovery between multiple transplant centres. We are particularly looking at the relationship between Spain and Portugal as Portugal appears to have similarities to Ireland in that it has a young national lung transplant programme plus an association with a more developed transplant programme in neighbouring country Spain.

Annual Conference & AGM 2008

Our Annual Conference and AGM took place in Drogheda at Boyne Valley Hotel and Country Club on 11-13th April. The Association would like to thank all the speakers who contributed to making the weekend very informative and successful and to the Drogheda branch for all the local arrangements and entertainment. We would like to point out that recordings of all presentations are available on our website as a video stream and that photographs of the conference are available under

the photo gallery on the website also. We would like to draw everybody's attention in particular to Dr Preston Campbell III's presentation from the CF Foundation where he discussed new CF drug therapies under development and under clinical trials in the USA. It was encouraging to hear him state that he believes that CF will become a disease that one will live with and not die from in the not too distant future.

Medical Facilities Update for PWCF's Across the Country

The Pollock Report highlighted the importance of appropriate patient facilities for PWCF when they receive both their outpatient and in-patient treatment. It was also highlighted that centres of excellence in CF care need to be appropriately resourced in centres around the country and to be able to relieve pressure placed on National adult and paediatric centres of excellence. The draft report of the HSE CF Working Group also supported these findings and subscribed to the recommendations of the European Consensus Document on CF care as the standard to which Ireland should strive to attain.

Progress is being made to get facilities upgraded in the major centres across the country. It is slower than what we accept but it still is progress.

Developments at St Vincent's University Hospital

An audit was carried out by the HSE in December 2005 that confirmed that St Vincent's was treating over half the adult CF population of the State. St Vincent's in contract to many other hospitals in Ireland currently only has a small number of single rooms relative to its overall bed allocation. This has caused serious problems for all patient groups that require isolation including cystic fibrosis patients. The HSE have acknowledged that PWCF need to receive their treatment in an environment which allows for appropriate infection control. Outpatient facilities for PWCF has improved considerably as a result of the opening of the first phase of the redevelopment of the hospital in 2006. The next phase of redevelopment covers in-patient accommodation. In this phase it is planned to replace 120 existing beds in multi-occupancy ward accommodation with a new building comprising single en-suite rooms and appropriate clinic and office space. This new building will provide accommodation for CF and other patients. Planning permission has been granted and it is intended that construction will commence at the end of 2008 and will take 24 months to complete. We are told that this project had been identified as a quick build

project and will be completed within the allocated time.

Various interim solutions have been looked at that included refurbishment of existing wards, a pre fabricated building and off site accommodation. The preferred solution currently is the provision of isolation rooms by refurbishing existing hospital facilities. Work has already commenced on the refurbishment of St Mark's Ward to provide eight single en-suite rooms for CF patients. In order for this work to take place it has required considerable reorganisation of care at the hospital, across all specialities and patient groups. This included the decant of the existing day ward from St Mark's and the relocation of the National Sleep Laboratory to enable free access to St Mark's Ward. The timeline for this project as received from hospital management is as follows:

- Designs drawn up – February 2008
- Decant of patients to allow contractor access to St Mark's Ward
- 10 patients discharged week commencing 17/3/2008
- 10 patients discharged week commencing 24/3/2008

- 10 patients discharged week commencing 31/3/2008
- Contractor started on site 18th March 2008
- Demolition commenced 5th /6th April
- Handover and completion by contractor 7th July
- Hospital equipping and commissioning to be completed by 31st July 2008.

A second interim phase will commence once the beds in St Mark's Ward have been released for patient occupation. This will involve the remodelling of St Camillus's Ward and the conversion of a number of existing 3 bed rooms into single rooms with ensuite facilities. The exact number of rooms has not been finalised as the architects and engineers are still researching all the options that are available to optimise space and to minimise patient and hospital upheaval during the remodelling process. It is expected that phase two would make an additional 10 beds available for CF. Architectural drawings for the interim Phase 1 developments have been received by the Association along with provisional drawings for Phase 2 and a schematic of the new 120 replacement bed block.



Developments at St Vincent's University Hospital - continued from page 2

The Association has not removed a prefabricated solution of providing further CF isolation beds from the agenda and the requirement for these is being reviewed regularly in conjunction with phase 1 and 2 of the interim CF developments.

SVUH Releases Statement On Home IV Treatment

A statement on home IV treatment was released by SVUH as a direct result of ongoing meetings between the patient liaison group and the hospital. The statement is as follows: Worldwide, prognosis for patients with cystic fibrosis has improved dramatically over the past few decades. One of the major reasons for improved prognosis is the early identification and aggressive treatment of CF exacerbations. The ultimate goal of all exacerbation treatments is to maximise lung function and nutritional status, both of which are major independent predictors of survival. This can only be achieved by early, aggressive treatment with antibiotics followed by close monitoring of response to treatment with input from all members of the multidisciplinary CF team. The treatment of CF exacerbations requiring intravenous antibiotics in the home setting is an important component of the management of patients with cystic fibrosis. We have an active home IV programme in St. Vincent's University Hospital and encourage the use of home IV therapy whenever possible. Each CF patient with an exacerbation is considered a potential candidate for home therapy with the decision about treatment location made at Consultant level. As a result, home IV are used whenever possible but it is important to realise that not all CF patients are suitable for home therapy. Examples of situations where hospital inpatient treatment is required:

- Patients with moderate to severe cystic fibrosis lung disease that could deteriorate rapidly and require close monitoring to ensure response to therapy.
- Life-threatening complications of CF including respiratory failure, haemoptysis (coughing up blood) and pneumothorax (collapsed lung).
- Presence of complications of CF that can increase the risk of poor response to antibiotic treatment or require in-hospital specialist input such as malnutrition, poorly controlled CF related diabetes and advanced CF related liver disease.
- Presence of antibiotic resistant bacteria that require multiple high-dose antibiotics to treat. Close monitoring is required to ensure

CFAI Sponsored Diagnostic Research to Become Mainstream

With support from CFAI a molecular scientist in cystic fibrosis commenced work in May 2006. The molecular identification and typing of *Pseudomonas aeruginosa* strains has so far been performed in the laboratory of Prof Seamus Fanning in UCD. The primary goal of this research was to improve the quality of service for CF patients. The initial focus was on the development and implementation of molecular techniques for identifying and typing *P. aeruginosa* from CF patients with the aim of incorporating these methods into the routine laboratory in a way that best utilises laboratory staff and facilities and maximises patient care. Ac-

response to therapy as well as the prevention of possible side effects from combined high-dose drug therapy.

- Failure to respond to home IV treatment in the recent past.
- Concerns regarding safety and compliance with home IV treatment.

At St. Vincent's University Hospital, many of our CF patients are treated with home IVs. The decision to treat a particular CF patient in hospital is usually made as a result of situations 1 to 5. These complications are far more common in adults CF patients compared to paediatric patients due to the progressive nature of CF.

Fortunately, many young CF patients who transition from paediatric hospitals to St. Vincent's University Hospital have mild lung disease and are excellent candidates for home IV therapy. These patients are treated with home IVs for exacerbations, and may continue to be treated in the home setting for years. Unfortunately, as they get older, home treatment is often no longer the best option due to disease progression and the development of the conditions outlined above.

It should be noted that, once our CF patients have shown a good clinical response to in-hospital treatment, the patients are often discharged home to complete the remainder of their IV antibiotic therapy in the home setting, so reducing hospital length of stay and freeing up hospital beds. The decision to discharge a CF inpatient home on home IVs is reviewed by the CF Consultant on a daily basis.

It is also worth noting that we have recently audited our use of home IV therapy in patients with moderate to severe CF lung disease. We have found that treatment delivered in the hospital setting leads to greater improvements in lung function and nutritional status than treatment delivered at home. These results are consistent with a number of published studies from other large CF centres, including Belfast and Manchester that have also shown that hospital treatment for CF patients with moderate to severe CF lung disease is superior to home IV treatment.

According to Dr Kirsten Schaffer, Locum Consultant Microbiologist at SVUH this research "has not only significantly improved the microbiological diagnostic services at St Vincent's University Hospital but has also allowed us to generate better infection control/isolation services for cystic fibrosis patients." Molecular diagnostic work will commence shortly on site in SVUH once their molecular laboratory is up and running. This is good news for those attending SVUH as it will contribute towards the better management of the segregation / isolation of patients and the prevention of cross infection.

Beaumont To Get Six CF Beds

A new building at Beaumont Hospital to include 28 single beds is scheduled to be completed by November of this year. The hospital have announced that 6 of the 28 beds will be for cystic fibrosis inpatients. This is in addition to the 6 day care beds and improved outpatient facilities that are to be provided also by the end of the year as a result of the allocation of €2m in capital funding to CF services at the hospital in the 2008 Budget. This is a major development for adult CF services regionally and nationally as Beaumont provides services to CF patients not just from the Dublin region but to patients living in the NE and other regions.

Cork University Hospital—Second Largest CF Centre for Adult CF Patients

CUH have been very fortunate in that the majority of adult CF patients have been able to get admission to single rooms and to avoid admission through A&E through a very proactive bed management process. The system is however under severe stress and the medical team realise that action has to be taken immediately to avoid problems within the next 18 months as the numbers of adult CF patients continues to increase. The medical team are currently finalising a Statement of Need that will be presented to the hospital and to the HSE. This will identify the immediate requirement for a day-care centre followed by the addition of en-suite single rooms. Considerable funds have been raised locally through initiatives of the Cork and Kerry branches and the Build4Life initiative that will be used to provide proper facilities at CUH. In addition to this funding from National activities provided a CFAI Clinical Registrar's post in cystic fibrosis at the hospital over the last year. This resulted in a measured increase in services to patients with cystic fibrosis and the board has approved the funding of an extension to this post for another year commencing July 2008.



Galway Developments Progress

Currently there is no respiratory physician employed by the HSE to provide care to adult PWCF's. A new respiratory paediatrician has taken up her post but the respiratory consultant with a special interest in CF along with other critical positions still have not been appointed. A special committee of the Galway branch has been established to drive forward the development of CF facilities at University Hospital Galway. Plans have been drawn up and the Galway branch are in active discussions with hospital management and the HSE.

Waterford Regional Hospital

The appointment of the CF Respiratory consultant with a special interest in adult CF care is still outstanding due to the dispute between the Ministry of Health and the Medical Consultants Unions. We have heard that some form of agreement has been reached as a result a large number of consultants post are due to be advertised shortly or have been advertised. There has been considerable concern among members served by Waterford Regional Hospital on the announcement of the departure of the CF nurse specialist. Ms Anne Goggin has been a huge support to patients and family in the region and she will be sadly missed. She played a key role in maintaining regional CF services during a time when there was no specialist consultant led services. The Association wishes her all the best in her future endeavours. We have received confirmation from both the regional HSE Network Manager and from the General Manager at Waterford Regional Hospital that the recruitment process has commenced to fill the CF Nurse Specialist position at the hospital as a matter of urgency. It has also been confirmed that interim cover arrangements are in place in the event that a suitable replacement cannot be found in time.

Our Lady of Lourdes CF Nurse Specialist Cover

Concern was expressed by members that there was the risk of no CF Nurse Specialist cover. Nurse Hanratty was on maternity leave. The Association has received confirmation from the Director of Nursing and midwifery that the recruitment process has now been completed and that Mr Brendan Colgan has been appointed to the post and will be effective prior to the current post holders maternity leave.

It has also been confirmed that Dr David Vaughan will be staying on at Our Lady Of Lourdes Hospital and will not be moving to Crumlin Hospital. This is good news for those children under his care in Drogheda.

CF Paediatric Facilities

It is vitally important that paediatric CF services continue to develop on a national basis. Dr Canny from Our Lady's Hospital for Sick Children (the National Paediatric CF Referral Centre) in a letter to the Irish Times outlined the importance of the availability of isolation rooms for children with CF and the importance of handing over patients in the best possible health at transition time to adult services. Crumlin Hospital has now prepared a preliminary proposal for 5 single en-suite rooms for CF patients. The Association is working with the hospital's management, consultants and the project office on the specification and design for these dedicated CF beds. A formal request from the hospital to the Association requesting assistance with this project will be received shortly.

Temple Street Hospital Fundraising Department have been undertaking a very active programme to raise funds for a new CF outpatients department. Planning permission for this structure has been received and it is reported that the building will be completed by January 2008. There still remains a requirement for improved inpatient facilities.

National Microbiology Referral Centre at Tallaght Hospital

A plan for the development of a National Microbiology Centre has been presented by Prof. Philip Murphy to hospital management. The Association has been supporting the "CFAI National Reference Laboratory" for the last number of years by supplying funding for a specialist CF microbiology technologist. (Funding from the Association is committed through to June 2009). This centre has been proving a free service to all CF units around the country and has contributed significantly to improving CF care in Ireland. The centre is also recognised internationally having published and presented CF research extensively. The CF Microbiology Centre has been providing services from within the existing hospital laboratory and by utilising equipment belonging to universities. The Association is waiting on a request to assist in the construction and equipping of a dedicated National CF Referral Lab on the hospital campus. This request will be presented to the board of the association upon receipt. We have had preliminary meetings with the hospital and believe that this project could be quickly and easily implemented.

Mid-Western Regional Hospital

Regional members have expressed concern regarding the periodic transfer of one of the CF Nurse Specialists to general ward duty. The Association has formally made representations to local hospital management and to the National Hospitals Office concerning this issue. We have requested a meeting to discuss the development of services regionally for both adult and paediatric services.

CF Working Group

No further progress has been made in securing a confirmed publication date for the CF Working Group Report. Multiple Parliamentary Questions, letters to the Minister, CEO of the HSE, and to the Chairperson of the Working Group have brought no results. It was reported recently that it was hoped to have this released prior to our Annual Conference. Unfortunately this did not happen. A meeting was arranged with the Chairperson of the Working Group for 7th May and this has since been rescheduled to the 28th May. The findings of our audit of CF multi disciplinary teams will be discussed at this meeting as there are discrepancies between what the HSE are reporting and what we have established from the centres themselves.

In a recent reply to a Parliamentary Question on our behalf the following reply was received from the Deputy concerned on 21st April.

"The HSE acknowledged much of the findings of the Pollock Report and secured revenue funding of €4.78m in 2006 and a further €2m in 2007. This funding equates to approximately 80 posts to enhance specialist CF teams in a number of centres throughout the State which also provide allied expertise for associated conditions including diabetes and liver disease.

"The HSE has adopted a focused approach to the ongoing filling of these posts. Critical posts funded in 2006 including Consultant Respiratory Physician, Physiotherapists, Dietician and Medical Scientists, have been filled at a rate of over 90%

An audit of new positions carried out by the Association currently disputes this situation. From what we can evaluate only 29 posts have been filled as a result of the 2006 funding and none from the 2007 funding. Our findings have been relayed to the HSE to give them an opportunity to comment and contradict our results. We realise that the majority of posts outstanding from the 2006 funding are Medical Consultants and these posts are still log jammed as a result of the ongoing consultants' dispute with the Department of Health. This however does not address the lack of activity on the 2007 funding. This issue will be discussed at our next meeting with the HSE.



Research

At the end of last year three projects were selected by an international peer review process for submission for co-funding by the Association with the HRB (Health Research Board). The selected projects were as follows:

Prof NG McElvaney – Altered expression and processing of Interleukin-18 in cystic fibrosis

Dr Barry Plant – Inter-individual variation in TLR-mediated innate immune responses in CF patients and its relationship with clinical phenotype

Prof C Gallagher - Gender Differences in Muscle Dysfunction and Electrical Muscle Stimulation in Cystic Fibrosis

We had hoped that we would have achieved co-funding for all three projects submitted. Unfortunately there was a cutback in funding being made available to the HRB so the total number of projects allocated to the MRCG (Medical Charities Research Group – which CFAI is a founding member of) funding project was substantially decreased.

The HRB selected Prof Gallagher's project for funding. The lay description of this project is as follows:

On average, females with cystic fibrosis have more severe disease than males and their life expectancy is less than males. Our recent research suggests that this may be partly related to greater abnormalities in muscle function in females. The first part of this proposal will study leg and respiratory muscle function in adults and children with CF and will examine the role of muscle function in causing symptoms and disability in CF. The results in females will be compared to results in males.

The second part of the study will examine methods to improve muscle function, exercise capacity and symptoms in adults and children with CF. We will use a method of electrical muscle stimulation that has been shown to be of benefit in patients with other diseases but has not been previously studied in cystic fibrosis.

The results of these studies in Ireland will be compared to results from our collaborators in Montreal, Canada. This is a collaborative research proposal involving adult and paediatric cystic fibrosis units in Ireland, University College Dublin and McGill University in Montreal.

Molecular Medicine Ireland was launched in April and with it 15 research fellowships were announced. One of these was awarded to RCSI for further studies into CF.

CF Sweat Test Developer Dies at 80

Dr. Lewis E. Gibson, a paediatrician and researcher who developed a safe, highly reliable method to test children for cystic fibrosis, and later helped refine treatments for it, died on April 15 in Sturgeon Bay, Wis. He was 80.

In the 1950s, Dr. Gibson helped to devise the Gibson-Cooke sweat test, working on an observation made by other researchers and by parents, that the skin of child patients with cystic fibrosis was unusually salty. High concen-

CF Registry

The official launch of the restructured CF Registry as an independent legal entity took place on 18th May. Speakers included Prof M Fitzgerald, Prof McElvaney, Linda Foley (CEO) and was chaired by Prof C Gallagher. You will recall that this was a recommendation of the FGS Report. Funding for the Registry by the HSE has been very insecure over the years. In 2007 the Registry ran up a considerable overdraft before funding was made available from the HSE. In previous years we covered expenses of the Registry from our own funds. This ran up an inter-company loan of €30,200 that has been reported in the Financial Reports of the Association. Funding for the Registry for 2008 has now been received and rather than putting the Registry under severe financial strain I would request that the board to approve the write off of this loan to the Registry. The Registry currently has approximately 80% coverage and by the end of the year they expect this to be close to or exceeding 90%. The Registry will now be able to provide very valuable data about CF in Ireland that is statistically relevant. Dr Preston Campbell at our Annual Conference stressed the importance of a registry particularly when it comes to monitoring clinical trials. The Association supports the promotion of CF clinical trials in Ireland and to get access to the latest treatments as soon as is safely possible. An added benefit of participation in clinical trials is the fact that clinical trials by themselves improve the quality of care due to the implementation of strict quality control principles.

Sweat Test Developer—continued

trations of sodium and chloride on the skin have subsequently become a leading indicator of the disease, which can clog the lungs with mucus and interfere with the pancreas, leading to severe digestive problems and death.

With another researcher, Dr. Robert E. Cooke, Dr. Gibson stimulated sweating by swabbing a small area of skin with an alkaloid called pilocarpine, and applying a weak electric current. Sweat could then be trapped on gauze or filter paper and analyzed, causing little discomfort.

The scientists published their findings in the *Journal Paediatrics* in 1959. The Gibson-Cooke test remains in wide use, alongside more recent and sophisticated tests developed in the 1990s to identify carriers of defective genes that cause the disease.

Dr. Thomas F. Dolan Jr., a professor emeritus of paediatrics at Yale, said that before the advent of Dr. Gibson's test, patients were often wrapped in a plastic bag in order to obtain a sweat sample, a practice he termed "sometimes ineffective, prone to overheating the child and certainly dangerous when you're talking about a 3-year-old being tested."

(*New York Times*—April 30th 2008)

Irish Hospital Innovation Awards 2008

The Association was nominated for an award at the Irish Hospital Innovation Awards 2008 that were held on 23rd April. These awards were established to broaden awareness of the need to constantly improve standards of patient care and patient safety and to recognise and merit innovation and significant contributions in the Public and Private healthcare sectors. The Association was nominated in the Innovation in Advocacy category. This award recognises the success of patient associations and special advocacy groupings in furthering awareness of special groupings in furthering the awareness of special interest issues that are key to continuing improvement and performance enhancement in the Irish Healthcare Sector. The finalists had to demonstrate sustained leadership and innovation in the delivery of their own stakeholder objectives. The finalists were World Health Organisation (Patient for Patient Safety), MRSA and Families Network and the Cystic Fibrosis Association of Ireland. The category winner was the MRSA and Families Network. It was a great honour for the Association to be nominated for this award and then to be chosen as a finalist.

Murdered Polish Friends Gave the Gift of Life to Seven

The mother of one of two Polish men brutally murdered earlier this year says her son is "still with her" because his organs have helped save the lives of others.

Pawel Kalite (26) and Mariusz Sz wajkos (28) were both killed in screwdriver attacks in Drimnagh, Dublin, on February 23. Relatives of the murdered pair agreed to donate their organs after their deaths and Pawel's family said that the donated organs had helped to save the lives of seven Irish people.

His mother Justyna Kalite said that her son was kept alive in a small way, because his heart and other organs were donated to needy people in Ireland.

She told reporters in her hometown of Ostrowiec Swietokrzyski: "Because of our decision to donate his organs Pawel is still with me. His heart is still beating and not everything has gone to dust."

Three middle-aged men have benefited from his heart and lungs. Two young women have each benefited from his kidneys.

Relatives of Mariusz Sz wajkos also made a quick decision to donate his organs.

The Irish Donor Network said it was eternally grateful for the families' decisions to offer their loved ones' organs for donation in a foreign country.

(*Irish Independent* — April 30th 2008)



Tax Relief On Health Expenses For Incapacitated Children

There are special tax allowances available for parents of incapacitated children, and not everybody is aware of the extent of them. This article summarises the key allowances available.

General

Medical (and some dental) expenses are allowable against tax at the marginal (i.e. top) rate. Thus a qualifying expense of say, €100, entitles a 41% rate taxpayer to reclaim €41 of the €100. It is important therefore that taxpayers are aware of the full suite of allowances, and claim for them accordingly.

What can be claimed for?

All qualifying medical expenses incurred may be claimed for. This includes expenses incurred for yourself, and from 2007 on, for any other person that you pay the bills for. Prior to 2007, you could only claim expenses incurred for yourself, and generally, for members of your family. However, expenses incurred for an incapacitated child are allowable both pre and post 2007.

The Revenue Commissioners have a comprehensive guide as to what is a qualifying medical expense. Generally speaking all "normal" medical expenses – GPs, Consultants, Hospital Expenses, Drugs etc qualify, provided of course they are not paid for by some other party (e.g. HSE) or an Insurance policy (e.g. VHI).

Some expenses also qualify which, at first glance might not appear obvious. This includes:

- Supply, maintenance, repair of any appliance used on advice of a medical practitioner
- Physiotherapy where prescribed
- Food products specifically for diabetics
- Home nursing

And specifically for incapacitated children:

- Travel costs incurred taking the child to and from hospital
- Travel costs incurred going to and from a hospital to visit a child – where such trips are shown to be essential to the treatment of the child
- Telephone allowance (€300 for 2007) where the child is being treated at home
- Overnight accommodation for parents at or near the hospital
- Hygiene products and special clothing subject to a maximum of €500 pa.

Notes:

Vouched bus, train, plane & taxi fares are allowable. If a car is used a mileage allowance of €0.36 per mile in 2007 (€0.35 pre 2007) is allowed.

The above lists are not exhaustive.

CF children are regarded as incapacitated.

Are there any exclusions?

For 2007 and subsequent years no exclusions apply.

Up to and including 2006, the first €125 (in the case of an individual claim) and the first €250

(in the case of a family claim) are not allowed. For 2006 and prior years, therefore, it can be worthwhile looking at the overall family medical expenses before deciding to make one family claim or a series of individual claims in respect of each family member. The choice of option is the taxpayers.

Are there any other tax benefits?

Yes, parents can also claim the Incapacitated Child Credit of €3,000 (2007). This is effectively a €3,000 discount off your tax bill.

Are medical expenses incurred outside the State allowable?

Yes, subject to certain conditions. Generally, if the expense incurred qualified in Ireland, it will likely qualify when incurred abroad.

How do I make the claims?

Either by:

- Claiming on-line via Revenues Online Service (ROS) – www.revenue.ie or
- Completing Form MED1 and submitting to Revenue or
- For taxpayers who complete Form 11 (generally non-PAYE) the amount of the claim should be entered on Panel 1 on the form.
- For the incapacitated child allowance you should either ring your local tax office or enter it on your tax return at the appropriate point.

Do I have to send in receipts?

No. But you must keep receipts for at least six years in the event of an enquiry.

What other records should I keep?

You should keep a record of all mileage claims – date of travel, destination, miles etc. This record should be kept for 6 years.

Do I have to wait till the end of the year to make a claim?

Not necessarily. Revenue have stated that where hardship arises from the necessity to incur medical expenses that the end of year requirement may be modified.

If I haven't made a claim for a previous year is there anything I can do now?

Yes. You are entitled to make a claim for allowances and/or credits for up to 4 years past. Thus, during 2008, you may claim retrospectively for 2007, 2006, 2005 and 2004. You may not claim for 2003. After 31st December 2008 you lose the right to claim for 2004.

Word of Caution

I have come across a case whereby a Revenue Official dealing with a claim proposed to disallow it on the basis that:

- The scheme applies only to Oncology Patients and not to children with other conditions

- The mileage involved was all incurred within the Dublin area, and the scheme was intended to "cover only long journeys, not short ones"

If the above approach is adopted by Revenue, parents are advised that they should refer the Revenue Official to the Revenue Commissioners Tax Briefing, Issue 68, April 2008. This document makes it clear that the scheme applies to Children with Permanent Disabilities.

In relation to mileage, the briefing specifies "unlimited journeys, to and from any hospital". In the case above, the Official was asked to define a "short" journey and a "long" journey – and in the end the mileage claim was accepted. As these types of claims apply to a small number of cases it is not surprising that some Revenue Officials are not familiar with the minute detail of the scheme.

The moral of the story is – don't necessarily accept the first ruling. The Revenue Commissioners are reasonable and once the basis for a claim is clarified all should be well.

In the case outlined above a claim for parking charges at the hospital was disallowed. Given that in some cases a higher proportion of the cost of visiting a hospital derives from parking rather than travelling, it seems inconsistent to allow travelling and deny parking. However, as the Tax Briefing does not refer to parking the Revenue Official in the case above applied a correct interpretation to the regulation.

David FitzGerald AITI

April 2008.

Anyone for a Game of Golf?

A Golf Classic in aid of cystic fibrosis will take place at Edmondstown Golf Club on June 6th 2008.

If you wish to enter a team please contact Joe Cooke on (01)2894659 or 087-8273728.

The cost for a 4 man team is €700.

Raffle tickets for this event are also available from Grace Barrett at CF House. A book of 5 tickets for €5.



Cystic Fibrosis Registry of Ireland Comments From Linda Foley CEO of CFRI

The worldwide trend in CF registry methodology is to create web-enabled databases.

In Europe, we are moving towards this target, and will achieve it within the next two years. Beyond Europe, there will be progression towards merging sets of data from various continents within the next decade. Assisted by larger and larger sets of data, researchers will be able to make more definitive statements about CF and answer more questions about treatments. These conclusions will have impact for PWCF all over the world. Analyses will be done faster and results known sooner when data is pooled from many national databases.

Ireland was the first country to launch a web-based registry. We are now in our third year to summarise and present data from the registry and we continue to enrol new patients. However, full "ascertainment", or enrolment is an issue for the CFRI (Cystic Fibrosis Registry of Ireland).

Each PWCF should consider whether he/she would like to enrol. Publications such as the Patient Information Booklet and the 'Frequently Asked Questions' section on the registry website, www.cfairegistry.org are designed to assist people to make this decision.

Each potential enrollee should be comfortable that their information is confidential and secure; and, that it will be used to answer fundamental questions about CF. We have taken extra steps to assure the security of the CFRI, through the use of an exclusive server at the Internet Service Provider and advanced encryption techniques.

The question, "Can CF registries help to analyse information that will result in improved treatments and a better quality of life for PWCF?" should be the fundamental query that we are striving to answer. My belief is that CF registries are an effective tool with the potential to accomplish this. Improved treatments will mean prolonged life.

Irish data from the CFRI demonstrates that over half of the CF population are diagnosed after 3 months of age. As a general principle, earlier diagnosis leads to improved growth and reduced therapy needs. That means that over 50% of our CF population is at a disadvantage at the very start. Newborn screening for CF would transform that situation. Furthermore, screening combined with early enrolment on the CFRI would mean that PWCF would be monitored from birth. Monitoring can detect negative trends and alert the clinician to make changes or intensify therapy.

We plan to have 90% enrolment on the Registry by the end of 2008.

If more PWCF were enrolled we could increase our knowledge about CF in Ireland as well as uncover many more interesting facets of our unique population.

I would encourage all PWCF to register or to contact the CFRI for more information. Enrolment on the CFRI will help everyone.

Hypertonic Saline Therapy for CF

We have been receiving information requests from some of the branches concerning hypertonic saline therapy and its use in CF therapy. The following information has been provided courtesy of the CF Foundation.

The Cystic Fibrosis Foundation funded a study in Australia to find out if inhaling a mist of hypertonic saline twice a day would help people with cystic fibrosis (CF). Hypertonic saline is extra-salty water that is sterile, so there are no germs in it. Because CF airways are known to lack enough salt and water, researchers thought a hypertonic saline mist would help clear the thick mucus from the lungs.

The results of this study were first presented at the 2004 North American Cystic Fibrosis Conference and now have been published in the *New England Journal of Medicine* with another article on the same topic from the University of North Carolina at Chapel Hill. This fact sheet will help you learn about this the Australian study. Please talk with your CF care centre team to see if a hypertonic saline treatment should be added to your or your child's routine CF care.

How was the trial designed?

People in the study were put into one of two groups. One group inhaled normal saline that was a 0.9% salt solution. The other group inhaled hypertonic saline that was a 7% salt solution. Both groups inhaled a bronchodilator drug (to open airways) then inhaled a sterile salt-water mist using a nebulizer twice a day for a year. During the study, the patients and investigators did not know who was inhaling normal saline and who was inhaling hypertonic saline. Patients were watched closely for any health benefits or any problems while inhaling either solution.

What were the results of the trial?

Both groups had better lung function during the study. However, those taking hypertonic saline had even better lung function than the people taking normal saline. Also, it was found that the people in the hypertonic saline group had fewer lung infections than the other group.

Were there any side effects?

The side effects that were noted by some people included coughing more, sore throat and chest tightness. (It is known that hypertonic saline can irritate the airways.) Your CF care centre team may want you to take your first dose of hypertonic saline while at the care centre. This is to ensure your or your child's lungs will not have problems from hypertonic saline.

Is hypertonic saline right for me or my child?

Your CF care team can help answer this question. The people with CF in the study were 6 years old and older and had mild-to-moderate lung disease. People with *Burkholderia cepacia* lung infection were not included in the study. Your CF care team can provide you with more

information and may do some tests.

Who should take hypertonic saline?

We do not know if hypertonic saline is safe for everyone. We do know that people who are 6 years of age and older, or who have an FEV₁ greater than or equal to 40% predicted might be able to take hypertonic saline. Before it can be prescribed, your CF care team will assess you or your child. Your CF care team can provide you with more information and may do some tests (sputum cultures) to see if hypertonic saline is right for you or your child.

Can I make my own hypertonic saline to inhale?

To help prevent any germs from getting into your or your child's lungs, and to make sure the solution contains the right amount of salt, it is strongly recommended that you only use hypertonic saline prepared by a pharmacy. Ask your CF care centre team which pharmacy in your area can fill a prescription for inhaled hypertonic saline. Also, do not forget to clean and disinfect your nebulizer.

How much hypertonic saline will be taken?

In the study, 4 ml of hypertonic saline was inhaled twice a day. A Pari PARI LC Plus[®] jet nebulizer and a PariPARI Proneb[®] Turbo compressor were used to inhale hypertonic saline during the study. Your CF doctor will prescribe how much and how often you should take hypertonic saline. Ask your CF care team whether you can use your nebulizer and compressor.

If hypertonic saline is added to my or my child's CF care, should other drugs be stopped?

Hypertonic saline is one more helpful "tool" in CF care. It may be used as a part of your or your child's regular CF treatment. It is not meant to replace other proven treatments. Do not stop any therapy before you talk with your CF care team. It is always a good idea to talk about all of your therapies with your CF care team to make sure that you or your child are always getting the proper treatment.

Can I save time and mix my other inhaled medications with hypertonic saline?

You should not mix any other medications with hypertonic saline. Unless your CF doctor or therapist tells you to do it, do not put two medications into your nebulizer at the same time.

What is in the future for hypertonic saline and CF?

We need to improve our understanding of how hypertonic saline is to be used. For example, we need to know if a different nebulizer would work better. Also, we need to find out if people who are sicker or younger than 6 years of age will benefit by taking hypertonic saline. The CF Foundation is currently undertaking clinical trials in children under 6 years of age.



CFAI Board of Directors

After the AGM each year branch and regional meetings are held to appoint branch officers and regional representatives to the Board of the Association, previously the National Executive Committee (NEC). At the first board meeting after the AGM, Officers for the New Year are elected from and by the regional representatives. A list of the current board members are listed below. It is very refreshing to see new blood coming onto the board and the Association would like to thank all those who currently and who in the past give and gave so much of their personal time to the Association. Honorary Officers will be elected at the first meeting of the new board

Officers 2007/2008:

Sean O'Kennedy – **Chairperson**

Mary Lane Heneghan – **Vice- Chairperson**

John Coleman – **Treasurer**

Majella Kelly – **Secretary**

Officers 2008/2009

Will be elected at the first Board Meeting

CEO

Godfrey Fletcher

The Branch is the building block of the Association and is made up of people who have been directly affected by cystic fibrosis. For newly diagnosed parents of children with CF and for those who just want access to friendly ear our network of branch contacts is a very valuable resource. An updates list of branch contacts is available on our website—www.cfireland.ie under Contact Us.

Board Members

Eastern Region

John Coleman

John Dolan

Ian Duffy

One seat vacant

Mid West Region

Kenneth Flanagan

Catriona Hayes

Midland Region

Ester L'Estrange

One seat vacant

Medical & Scientific

Prof C Gallagher

North Eastern Region

Tess Brady

North West Region

Seán O'Kennedy

Tracey O'Kennedy

One seat vacant

PWCF

Brendan Lonergan

Nathan Swan

South East Region

Carmel Delaney

Anne O'Rourke

Southern Region

Ann Aston

Joe Browne

Paul Higgins

CF House
24 Lower Rathmines Road
Dublin 6

Phone: 01-4962433
Fax: 01-4962201
E-mail: info@cfireland.ie
Web: <http://www.cfireland.ie>

© Irish National Association for Cystic Fibrosis a company limited by guarantee trading as The Cystic Fibrosis Association of Ireland.

Registered Company Number: 449954. Charity Number: CHY 6350.