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CORK INFORMATION DAY

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DEVELOPMENTS

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He said that, amazingly, there had not been any controlled trials conducted to show that steroids work in Idiopathic Pulmonary Fibrosis and most physicians will not now use large doses of steroids over a long period of time. However, during periods of acute deterioration, where there is a flare-up of inflammatory activity in the lungs, a high dose of steroids for a short period may be needed to quell the exacerbation.

The tendency now is to refer patients with IPF for consideration for lung transplantation at an early stage, if the patient is under sixty-five and there is no response to a short course of medical therapy, as IPF tends to progress more quickly than other lung diseases.

At the Information Day Dr. Henry outlined the service that he and his colleagues, Dr. Barry Plant and Dr. Des Murphy, provide in the dedicated interstitial lung disease clinic at CUH. It is a consultant-provided service and over the past four years they have seen about forty-two patients with pure Idiopathic Pulmonary Fibrosis – that is pulmonary fibrosis for which no particular cause can be identified.

GUIDELINES FOR MANAGEMENT

Dr. Henry recommended the joint Irish, British and Australian Guidelines on the management of Interstitial Lung Disease, and said that they were as up-to-date and evidence-based as possible. These guidelines can be accessed via the British Thoracic Society website www.brit-thoracic.org.uk/ and there is also a link to them from the ILFA website www.ilfa.ie

PULMONARY REHABILITATION PROGRAMMES

Dr. Henry said that in Cork he has started enrolling IPF patients in a Pulmonary Rehabilitation Programme. These programmes of exercise and education were originally developed for patients with Chronic Obstructive Pulmonary Disease (COPD) but recent studies suggest that patients with IPF could also benefit from this type of programme.

He cited a study carried out in 2006 by Dr. Tim McDonnell and Dr. Seamus Donnelly of St. Vincent's Hospital in Dublin that showed that walking distance, breathlessness and quality of life all improved as a result of participation in a rehabilitation programme.

INFORMATION DAY



Terence Moran, Chairman of ILFA with Dr. Mike Henry at the Cork Information Day

Also speaking at the Information Day in Cork **Professor Jim Egan** said that because IPF was a relatively unknown condition it can cause a lot of anxiety and distress to patients and their families as there may not be an obvious path of treatment available.

He echoed Dr. Henry's point in relation to steroids, saying that it was remarkable that an appropriate evaluation of their use for IPF had never been done, but he said that in the past ten years considerable progress has been made by specialist clinics like the one in Cork. The patient-oriented treatment studies that had been carried out in these centres had made a significant difference and had taught a huge amount about the condition, in particular about how to use treatments.

Professor Egan thanked ILFA for playing a central role in supporting this research. He said that Pirfenidone, the most encouraging up-coming drug, was going for FDA approval in the United States on 9 March this year and could become available thereafter. "However," he said, "Pirfenidone it was not a silver bullet. The key need is to get more treatments."

LUNG TRANSPLANTATION

Professor Egan said that lung transplantation had now become a very important treatment for IPF. Regrettably, however, because IPF can progress very quickly many people do not survive long enough to avail of this treatment. Of the twenty-five lung transplants carried out in Ireland to date twelve were on IPF patients. Professor Egan said that, while this was an improvement, it was still not good enough, and there was a need to increase the number of transplants being done. He pointed out that Ireland was the only country in Europe without a formal transplant organisation and he commended ILFA who, with other advocacy groups, were lobbying to achieve legislation and a proper structure to oversee transplantation in Ireland.

LUNG FIBROSIS AND CONNECTIVE TISSUE DISEASE

Dr. Sinead Harney, Consultant Rheumatologist at Cork University Hospital, spoke at the Information Day in Cork about lung fibrosis associated with connective tissue diseases such as rheumatoid arthritis, scleroderma and lupus. She said that over half the patients with rheumatoid arthritis had some form of lung disease.

She said that usually people who have an underlying cause for their lung disease do better than patients who don't.

Dr. Harney and Dr. Henry have been running a joint clinic in CUH since 2007 so that patients can be seen by a respiratory and a rheumatology expert at the same time. She said that this sort of joined-up approach will, hopefully, lead to better outcomes for patients who have lung fibrosis associated with connective tissue disease.

MARATHON RUNNERS FOR ILFA



Anne-Marie Harris ran her first Dublin City Marathon for ILFA.

She was joined by Ann Docherty who came from Scotland to run in memory of her Uncle Leslie Knight. "ILFA gave Uncle Leslie and his family such support throughout his illness and it seemed a great way to remember him."

And a special thanks to Andrew Grehan who ran his fourth successive Dublin City Marathon in memory of his aunt, Denise Cassidy, and has raised substantial funds for ILFA.



On November 28th last, Con and Mary Minihane of Baltimore Yacht Charters, hosted a coffee morning on board their yachts "Inisbeg", "Inisceim" and "Inisleigh" at the pier in Baltimore on ILFA's behalf. People came in great numbers with foodstuff, donations and raffle prizes. Great fun was had by all and most importantly €2,337.42 was raised for ILFA.

Front row: John O'Halloran, Nuala O'Halloran, Mary Minihane, Marian Neylon
Second row: Mary Cottrell, Tara O'Neill, Eileen O'Sullivan. Third row: Maura O'Regan, Eddie Fitzgerald, Celestine O'Loughran, Mary Jordan, Ian Crawford.
Back row: Kieran Collins, Becky Garcia

EXERCISE TIPS

At the Information Day in Cork Irene Byrne, Senior Physiotherapist with the Irish Heart Lung Transplant Programme, spoke about the importance of exercise for patients with IPF. She said that breathlessness should not stop a person exercising - moderate breathlessness is normal and acceptable.

Here are some of her tips for exercising:

A Pulmonary Rehabilitation Programme can get you started with an exercise programme that is designed for your needs but it has to be continued on a daily basis.

Make your exercise programme as important as your medication. Fitter muscles will use less oxygen.

Accumulate exercise regularly over the day, every day.

If you have an illness or an exacerbation of your condition you may have to discontinue your programme for a time, but then build up slowly again with regular easy-going exercise.

Choose your time to exercise. Very cold, very hot or very humid weather can affect your ability to exercise and the old adage of not exercising for an hour after a meal holds true.

Use oxygen when exercising - you'll get further and get more mileage- and adjust the level of your oxygen to match your level of activity.

When it comes to daily living activities don't waste energy. Plan ahead and give yourself plenty of time to do things.

Sit rather than stand. Use a seat in the shower, or when shaving.

Use oxygen when showering and dressing and don't be adverse to using a wheelchair to go from A to B so that you conserve your energy to do the things you really want to do - be it shopping, going for a meal out, or visiting friends.



A NIGHT OUT AT THE GUINNESS HOP STORE FOR ILFA

The International Women's Committee Dublin are organising a fundraising event for ILFA at the Guinness Hop Store, St. James's Gate, Dublin on FRIDAY 16 APRIL. The evening will start with a tour of the hop stores at 7.30pm, followed by supper at the gravity bar, where you can enjoy a panoramic view of Dublin city and live jazz music. Tickets are €50 and include tour, supper and two drinks. Contact Claire at cpctunissen@hotmail.com or at 087 7593251

ILFA NEWSLETTER



Irish Lung Fibrosis Association

Patrons: Brian O'Driscoll, Charlie Bird
Issue: March 2010 Volume 7 Issue 1

WICKLOW 200K

The countdown is on to the Wicklow 200k Cycle which will take place on Sunday, 13 June, and entry forms are now available on www.wicklow200.ie

This year's start/finish will be in Greystones and the route will be largely the same as the 2009 route with the return from Rathdrum via Avoca and Ashford.

Once again Professor Jim Egan plans to take on this challenge to raise funds for ILFA, although his training is somewhat behind as a result of a skiing accident earlier this year! You can encourage Professor Egan by sponsoring him through the ILFA website www.ilfa.ie or by contacting ILFA at 086 8715264 or 086 0570310

TABLE QUIZ FOR ILFA

Thanks to Emmet Lynch and his family who organised a Table Quiz in Co. Armagh Golf Club on November 20th and raised over €1,000 for ILFA.

The Quiz was organised in memory of Emmet's brothers-in-law, Fr. Eamonn Cowan, who was Chaplain in St Patrick's College, Drumcondra, and Leo Cowen, both of whom had IPF.



PLAYING FOR ILFA. Doreen Grocock and the Dublin Orchestral Players raising funds for ILFA at the Dundrum Shopping Centre before Christmas

THE FLORA WOMEN'S MINI MARATHON 2010

Once again we are asking for your support for ILFA's main fundraising event of the year. Our services to members depend completely on fundraising and particularly on the funds raised by you who, year after year, do the WMM for ILFA. The 2010 WMM will take place at 3pm on 7 June this year. The closing date for entries is 27 April, or earlier if the target number of entries is reached before then, and entry forms will be available on-line, or in the Evening Herald every Wednesday and Saturday, from 3 March. If you can join us this year, or better still if you can organise a group of friends to run or walk for ILFA, we can supply you with Sponsorship Cards, T-shirts, Balloons. As many as you want! Just contact Nicola at 086 0570310 or at our email address info@ilfa.ie.

ON-LINE SPONSORSHIP

If you wish you can create your own fundraising page on www.MyCharity.ie which you can then email to your friends who can sponsor you on-line. It's really easy – no mess, no hassle- and the sponsorship money will go directly to ILFA. As usual we will be meeting up for the annual ILFA group photo beforehand at 2.15pm at Leeson Street Church and we will, no doubt, be adjourning to some local hostelry for refreshments afterwards. Further details of this will be posted on the ILFA website www.ilfa.ie



Even though the Annual ILFA Swim had to be cancelled because of the dreadful weather a few hardy stalwarts went ahead and swam anyway. Here they are pictured warming up afterwards in the Eagle House where they were met by ILFA Treasurer, Marie Sheridan, and her daughter, Chloe. From left Marie, Honora, Mary, Gabriel, Chloe and Colin.

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