

CONSENT FOR ORGAN DONATION

The Minister for Health and Children, Mary Harney, T.D., and her Department, have just concluded a consultation process on the issue of consent for organ donation. Members of the public and interested bodies were invited to submit their views on whether there should be a change from the current opt-in system, sometimes called a voluntary consent system, to an opt-out one, where people are presumed to have consented to their organs being used after their death unless they have indicated otherwise.

ILFA's SUBMISSION

ILFA in its submission said that, ideally, it would favour the adoption in Ireland of an opt-out system with family consultation - similar to the system that operates in Spain - the country in Europe with the highest organ donation rate.

At a meeting held as part of the consultation process in Dublin Castle on 13 February Professor Jim Egan pointed out that the available evidence suggests that an opt-out or presumed consent system is associated with increased organ donation rates in the countries where it has been introduced, even when other factors are taken into account.

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ILFA St. Stephen's Day SWIM



ILFA patron, Charlie Bird with Orla Bird and Rob O'Dowd after their swim.

The ILFA Annual Swim took place on St. Stephen's Day, 2008. It was a bright sunny morning on Sandycove pier, so much so that ILFA swimmers had to vie to get into the water with lots of other swimmers all wanting to take the plunge. ILFA volunteers were easily identified, though - in their trendy ILFA swim hats!

Among the ILFA swimmers was our patron, Charlie Bird, who jumped in with his daughter, Orla. It could not have too bad as Charlie was prepared to get in for a second time!

The wonderful hamper kindly donated by O'Shea's Public House in Balbriggan was won by David Buggy and, as usual, the Sandycove swimmers enjoyed the hospitality of the Eagle House in Glasthule afterwards.

About twenty-five hardy souls in all participated in the swim at Sandycove and over in Bettystown Ann Reynolds and her twenty companions kept up their Stephen's Day tradition on behalf of ILFA.

DEVELOPMENTS

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However, ILFA acknowledges that the public response to a change in the system of donation is of vital importance so, following our meeting with the Minister and her officials in November 2008, ILFA commissioned Lansdowne Market Research to include two questions in one of their omnibus surveys to get an indication of the public's reaction to a possible change in the system of organ donation from an opt-in to an opt-out system.

When asked if they carried a donor card, or if they had indicated in their Driving Licence what their wishes were regarding organ donation, 27% respondents said YES, they had, and 72% said NO, they had not.

When asked whether they would prefer an opt-in/voluntary consent or an opt-out/presumed consent system 67% of respondents favoured the current opt-in system as opposed to 27% who said they favoured an opt-out system.

It would appear from these results that the climate may not yet be right for the successful introduction of an opt-out system in Ireland.

ILFA, therefore, proposed that, in the context of a voluntary opt-in system being maintained, a system of required request should also be introduced whereby all potential donors, or their families, would be asked, by a suitably qualified person, if they would agree to donate. There is anecdotal evidence to suggest that many families who find themselves in this situation would like to be asked about organ donation but are not.

In its submission ILFA emphasised that of much more importance to ILFA members are measures to improve the rates of organ utilisation and in particular the utilisation rate of donated lungs.

This is particularly relevant in the context of lung or heart/lung transplants where the time frames are acutely short. Ireland already has an organ donation rate that compares favourably with other countries in the EU, but the utilisation rate of donated lungs is among the lowest in Europe.



As lung transplantation is the only effective treatment currently available for patients with Lung Fibrosis, a debilitating and terminal lung condition with an incidence rate of 5 per 100,000 of the population, increasing the utilisation rate from current donors could improve the situation significantly for Lung Fibrosis patients.

NEED FOR A TRANSPLANT AUTHORITY

ILFA strongly believes that any legislation in this area should be underpinned by the establishment of a statutory Transplant Authority that would take responsibility for co-ordinating the whole area of organ transplantation. The remit of such a body should include a review of the current practices for maintaining organs for transplantation to ensure best practice is implemented in all hospitals; the continuing and on-going auditing and monitoring of organ donation and transplantation rates; the setting of standards and agreed performance indicators for organ donation and utilisation to be implemented in all relevant hospitals; the training and strategic deployment of transplant co-ordinators nationally; the organisation of Public Awareness Campaigns to increase the level of registered donors in the population and the development and maintenance of a Register of potential organ donors.

To see ILFA's full submission on consent for organ donation go to www.ilfa.ie.

SOME GOOD NEWS

A recent study of the drug PIRFENIDONE, one of the new compounds being investigated for the treatment of lung fibrosis, is showing positive results. The Mater Hospital in Dublin participated in this international research study and a number of Irish patients were enrolled in it.

An anti-fibrotic agent, Pirfenidone was originally developed by a biochemist in his garage in California. It has since moved through various research stages. Because of the dearth of effective medical treatments for lung fibrosis these promising results are good news for all IPF patients.

WICKLOW 200K CYCLE

Is Professor Egan a glutton for punishment?
It looks like it!

He has volunteered to do the Wicklow 200K cycle again this year and anyone who knows anything about the Wicklow Mountains knows what a challenge this is!

Billed as Ireland's premier cycling challenge the 200km route goes from Belfield Campus in Stillorgan to Enniskerry and on to Blessington via the Sallygap. Then over to Aughavanagh, up Glenmalure, and back through Roundwood to Enniskerry. And that's not the end of it – you still have to make it back to Belfield. Whew!

The total climb is over 2,000 metres.

Each year this event attracts over 1000 cyclists, including ex-professionals, from many different countries. The cycle this year will take place on Sunday 7 June. It starts at the UCD Campus in Belfield at 7am and riders are allowed 14 hours to complete the route although most finish well within that time.

So come on and get behind him with your sponsorship. Let's make the pain worth his while! You can sponsor Professor Egan on-line by logging onto the ILFA website at www.ilfa.ie or by calling us at 086 8715264 for sponsorship cards.



David Buggy with his son, Jack, and a friend before they took the plunge for ILFA.



THE FLORA WOMEN'S MINI MARATHON 2009



Yes, it's that time of the year again! This year's Women's Mini Marathon will take place on Monday, 1st June, at 3pm.

The WMM is ILFA's largest fundraising event bringing in over €130,000 since 2003, money that has been used to fund research into new and better treatments for lung fibrosis. Last year women from all over the country came together and raised over €25,000 for the ILFA research fund and had lots of fun as well. Those of you who have joined us before will know what a great day it is and we hope you'll all join us again this year.

As usual we will be meeting beforehand at Leeson Street church at 2.15pm for the annual photo shoot and we will be adjourning for refreshments to some local hostelry afterwards – details will be announced on the ILFA website www.ilfa.ie nearer to the day.

If you would like to join us this year, or better still if you can organise a group of friends in your local area to come along with you, ILFA can supply you with sponsorship cards, T-shirts or vests, and even balloons- as many as you want! Just contact us at our email address info@ilfa.ie, visit our website www.ilfa.ie or telephone 086 8715264.

ON-LINE SPONSORSHIP

It's easy to create your own fundraising page on www.MyCharity.ie. You can then email your page link to your friends who can sponsor you on-line. The money will go directly to ILFA.

IMPORTANT!!!

The closing date for registration for the WMM is 21 April or when the maximum number of registrations has been reached, so go on-line now at www.womensminimarathon.ie or get an entry form in Wednesday's or Saturday's Evening Herald to make sure you are not disappointed.

DON'T DELAY – ENTER TODAY!

OLIVIA MC CANN. It was with deep sadness that we heard of the untimely death of Olivia McCann from Lung Fibrosis. ILFA would like to extend our condolences to Olivia's family and friends at this difficult time. May she rest in peace.



ILFA'S NEW LOOK WEBSITE

You may have noticed that we have redesigned our website. If you haven't why not log on to www.ilfa.ie and let us know what you think. The new look was designed by Flo Web Design.

We would like to thank them, but we would particularly like to thank John Cogan for all his work in initially setting up the ILFA website and for his endless patience in helping us to maintain it. Thanks John!

MOUNTMELICK CYCLE

Tom Flynn, an IPF sufferer, was the recipient of a lung transplant in September 2005. On the anniversary of his transplant in September 2006 he cycled from his home in Mountmellick, Co. Laois, to the Mater Hospital in Dublin to show his gratitude and also to raise funds for the Heart and Lung Unit.

Tom is back on his bike again and is organising another cycle from Mountmellick to Dublin on Saturday, 30th May, to raise funds for ILFA and the Irish Heart and Lung Transplant Association.

If you are interested in joining Tom on his cycle for any part of the route – you don't have to do the whole 50 miles- you can contact him at 086 1500970. He would also be delighted to hear from anyone who would like to sponsor him. It's in a good cause!



John Donnelly (right) relaxing after his walk with a well-deserved cup of tea!



BETWEEN THE BRIDGES

Congratulations to John Donnelly and his friends, ranging in age from 13 to 75, who completed the Between the Bridges Walk in Belfast on Sunday 8 March.

The walk was to celebrate the opening of a new section of the Dublin Belfast m1/westlink which was officially opened after 4,500 people had walked 10k/5k along it to christen it. John, a lung transplant recipient sent us the following report: *'We all arrived through the sleet showers at 9.15 am and parked our cars. It was 2 degrees with a cold wind but it felt like -10C. At 09.55hrs to our delight the sun came out and loads of clothes came off. The horn sounded and we all walked and talked our way along the closed M1 motorway in the bright sun with a nice breeze at our backs. However on the half-way turn around everyone was caught out by the wind in their faces and all paces slowed to suit. There were old people, young couples with kids in tow, girls with prams and real athletes. I was feeling so elated and so aware of my lung donors life giving generosity and I was determined, as I am every day, to use my gift to the full as part pay-back.*

Eventually the only thing between me and the red finishing line was a long slope under a bridge and up the other side. Walking with my doctor daughter-in-law who was checking me constantly and was invaluable on the inclines and my granddaughter who encouraged me all the way with her craic was very enjoyable. Needless to say all my team applauded me as I broke into a run for the line. I can remember few things better than this walk for ILFA.'

John and his wife, Alice, were still feeling the buzz when he returned for his check-up to the Mater the following Tuesday. John said that although he felt a bit tired after the walk it had been a wonderful day. We were glad to hear that all his test results were good!