

Drama Fund-raiser

Tubber Drama Society staged their production of “Not Tonight Darling” in Tuar Árd Moate on Sunday 19 April 2009 in aid of ISARC. The total proceeds of the night realised €1020. The production was hilarious and thoroughly enjoyed by all. Many thanks to everyone in Tubber for giving their time free of charge and especially Joe Lowry who is associated with ISARC.

Helpful tips for newly diagnosed sarcoidosis sufferers.

For many newly diagnosed sarcoidosis patients, talking to their doctor can present unusual challenges. For some, the first time they have heard the word ‘sarcoidosis’ is when they are diagnosed. In addition, some sarcoidosis patients may see more than one doctor to treat their disease.

Good communication with your doctor may mean that your treatment plan is more successful. For doctor visits it is important to remember the path to good health: *Prepare; Ask Questions; Take Notes; and Honesty is the best policy.*

PREPARE: Before you go to the doctor write down a list of questions that you want to ask during your visit. Bring information about tests you have had in the past and medications you are currently taking. Be sure to include any vitamins or alternative treatments you receive. It is also a good idea to make a list of all new symptoms, even if they do not seem important.

ASK QUESTIONS when you do not understand what your doctor has said or understand the meaning of a word (like granuloma). Some questions to ask your doctor after you are diagnosed, might include:

- **What medications or treatments are available to help me?**
- **What are the benefits and side effects of these medications?**
- **How do I know that my treatment is working?**
- **What will happen to me if nothing is done?**
- **Do I need to see a specialist?**

TAKE NOTES: If you are nervous, it may be difficult to listen and understand the information your doctor gives to you. Plan to bring paper and a pen to the visit with you.

SHARE THE BURDEN: It’s always helpful if a relative or a close friend can be with you if you feel nervous or anxious about understanding the information.

Some Dates for Your Diary

Wednesday 6th January 2010:
ISARC Support Group Meeting.
Awaiting confirmation of speaker.

Wednesday 3rd February 2010:
ISARC Support Group Meeting.

Wednesday 3rd March 2010:
ISARC Support Group Meeting.
Talk by Mrs. Barbara O’Connell, Pharmacist, on the drugs used in the treatment of sarcoidosis.

Wednesday 7th April 2010:
ISARC Support Group Meeting.

Wednesday 5th May 2010:
ISARC Support Group Meeting.
Talk by dietician.

Wednesday 2nd June 2010:
ISARC Support Group Meeting.

Sunday 4th July 2010:
The Marian Geraghty Trust Run
at the GAA Centre Mount Bolus village.

Wednesday 7th July 2010:
ISARC Support Group Meeting.
Talk by Respiratory Nurse Specialist.



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ISARC

IRISH SARCOIDOSIS SUPPORT NETWORK

Newsletter

November 2009

Edition 06

Dear Supporters

A very warm welcome to the sixth edition of the ISARC Newsletter. Newsletters are a great way of keeping people updated, especially for those who are unable to attend a support group meeting or do not have access to the internet. So please share your stories or give us your views on what you would like to see in future newsletters. In this edition Karolien Verheyen has shared her own personal story with us.

It is with pleasure that I can now inform you, that on the 29th May, Mick O'Connell, the Kerry football legend officially launched the South West Branch of ISARC in Tralee Co Kerry. Dr. Seamas Donnelly, St. Vincent's University Hospital Dublin and Dr. Terry O'Connor from the Mercy Hospital Cork, both Respiratory Consultants gave a talk on the clinical diagnosis of Sarcoidosis and the outcome of recent research into sarcoidosis. Both talks were found to be very interesting and informative. Karolien Verheyen is the facilitator of the Tralee branch. They have had two support group meetings since the launch and had a very good attendance at both. I wish Karolien and the group in Tralee the very best of success for the future.

The 6th Annual Marian Geraghty Sarcoidosis Memorial Run took place on Sunday 5th July in Mount Bolus. It was well supported with over two hundred people participating on a very pleasant Sunday afternoon. Young and old turned out for the event in their numbers and it was great to see an increase in the number of runners from the local athletic clubs.

A party of over thirty people travelled over from England for the event.

On the Sunday 9th August we were very fortunate in being given the charity spot at the Tullamore Show. It was a case of third time lucky, the two previous years had been a total washout. We had a very busy day, meeting lots of people who had sarcoidosis, most were totally unaware that a support group existed in Ireland. They were delighted to learn about ISARC, as most thought that they were the only people who had the disease. This certainly highlighted that there was a need to **increase public awareness of sarcoidosis in Ireland**. We managed to raise in excess of €1250 on a raffle at the show and I would like to see this money go towards setting up our third group in the South East i.e. Kilkenny. We would like to thank Michael Scully and Kilcormac/Killoughey GAA club for donating the All Ireland tickets.

A number of fund raising events were organised during the year. I would like to thank the following: Bridie Byrne, Ballyfin, (Cake & Flower Sale); Sean Lowry, Shannonbridge, (Tubber Drama Group); Michelle Hartnett, Crinkle, Birr (Dublin City Marathon); Mary Smith, Daingean (Card Drive & Car Boot Sale).

There work raised funds and more importantly increased public awareness. The money is now in place for the research program which will look at the prevalence of sarcoidosis in the Irish population.

A lot of work needs to be done and we need much more help to try and maintain, but also expand the support groups. So I ask you, to please get in touch with us and let us know if you are interested in getting involved in the running of ISARC. This would share the work load and bring new ideas/skills to the group. My grateful thanks to you all for your help and support over the past few years.

I would like to take this opportunity to wish you all a very Happy Christmas and a Prosperous and Healthy New Year.

Mary Walters

Mary Walters



SPEAKERS: Speakers at the Irish Sarcoidosis Support Network in the Brandon Hotel, Tralee, on Friday evening. (r): Mick and Diarmuid O'Connell (Valentia), Dr Seamas Donnelly and Dr Terry O'Connor.

'I had never even heard of sarcoidosis'

(28th July 2009 - The Kingdom)

WHEN it comes to silent diseases there are few to compare with sarcoidosis, particularly as many sufferers have never even heard of the condition.

Caherciveen's Karolien Verheyen knows just what that feels like. The 32-year-old first noticed a problem 15 years ago but having never come across sarcoidosis before was only diagnosed in 2007.

Despite the fact that it is relatively unknown among most of us, sarcoidosis actually affects thousands of Irish people, mostly aged between 20 and 40 and can affect any organ of the body, although it most commonly affects the lungs, eyes, lymph nodes and skin.

For the Caherciveen based tutor and music teacher problems were mostly centred around her lungs and breathing.

"In my case the disease was chronic with a slow progression. It was difficult to notice since I was always swimming, walking and cycling.

"I had breathing difficulties for a long time, since I am 17, but it started getting worse when I was about 21 - I was smoking at the time but did not feel quite right I had problems with a stuffy nose, throat, feeling cold all the time, I was tired, it was hard to concentrate, I was sleepy," Karolien recalled.

It was not until 2007 however that problems intensified on her return to Ireland from a holiday in Cuba.

"I took my return flight on May 1, 2007 and landed back in Kerry on the May 2. The next day I would start work in Tig an Oilean - a centre for people with Down Syndrome where I facilitated music sessions already," Karolien explained.

"On the evening of May 3 everything started getting very bad; I could hardly breath, I was coughing constantly, I was exhausted," she added.

It wasn't until July that the Caherciveen musician finally went to her local GP, and after that it took six long months of intensive tests to get the diagnosis.

There were blood tests, sputum tests, spirometer, antibiotics, X-rays, then a CT scan with eventual referral to a respiratory physician at the Mercy in Cork. Then an ECG, physical examination and broncoscopy with the final diagnosis of sarcoidosis stage III in December.

For the majority of patients (up to 90 per cent) Sarcoidosis develops in it's acute form but for Karolien it was chronic building up gradually.

"I had never heard of sarcoidosis before," Karolien admits.

"I felt terrible for years where everything was a struggle, where doing the smallest thing required enormous amounts of energy. You lose your confidence because you don't understand what is happening and others don't either.

"You are too tired to do anything fast, people get angry with

you because of that and you get frustrated because you are doing your best but you just cannot focus. It is a snowball effect where you feel old but you are young," she added.

Since her diagnosis the Caherciveen woman has been receiving treatment for the condition, for her this means medication in the form of corticosteroids, stomach protector and medication to prevent osteoporosis plus a bronchodilator and steroids in one inhaler.

Finding support from people who understand the condition has been important for Karolien, she attended a support group in her native Belgium and later the Irish Sarcoidosis Support Network which recently launched its Southwest branch.

"It was a relief to meet with fellow patients but some people were very negative and made me a bit scared," Karolien recalls.

"My friends in Belgium and Ireland and my family have been a great support to me - I could not have done it without them," she added.

Now however Karolien chooses to see Sarcoidosis as a positive in her life, embracing the good things it has brought with it.

"It is part of my life and I am embracing it as a gift," Karolien revealed.

"It made me meet many new people, including handsome consultants, start studies in Human Biology with the Open University, take a new look at life; with no fear, more strength and more confidence," she added.

"I have learned a lot about myself since the diagnosis, I have also learned a lot about people's attitudes and assumptions," the Caherciveen woman stated.

"This is not an easy disease since it so silent. You look well and healthy but everyone is unaware of the fact that you are on treatment and that there is permanent damage done. I still get people who tell me I am unfit, after climbing a staircase, it makes me angry and I feel like explaining to them how I feel," she added. However after years of feeling stressed and worried Karolien now feels positive and strong, and hopes that her confidence will inspire other sufferers.

"For people with sarcoidosis my message is to hold on, look forward, be calm within yourself, rest on time," Karolien advises.

"You yourself are the best doctor you will ever meet so listen

to your own body," she concluded.

Lifeline launched for sarcoidosis sufferers

LALUNCH: Karolien Verheyen has set up the first South West sarcoidosis support group, launched in the Brasserie Hotel, Tralee, on Friday night.

Sarcoidosis sufferers in the county now have a new lifeline with a support group launched in Tralee on Friday night. From feeling extreme fatigue to fever, weight loss and shortness of breath, sufferers may not even be aware of their condition, according to organisers.

By MICHELE CULAN

On Friday evening, Mick O'Connell officially launched the south west branch of Irish Sarcoidosis Support Network (ISSARC) in the Brandon Hotel with Dr. Seamas Donnelly from Dublin and Dr. Terry O'Connor from Mercy Hospital in Cork who both held presentations on current research and the diagnosis of sarcoidosis. "All GPs from Kerry Limerick and Cork were invited to attend as well as sufferers and their families," said co-ordinator of the new south west branch and sufferer, Karolien Verheyen.

SYMPTOMS

And, according to Karolien, the new group is here to help. "Symptoms can vary and everyone is different," she said. "I was only diagnosed in 2007 yet had suffered bad health for ten years. Each year I had getting worse

definitely wrong."

According to Karolien, the cause of sarcoidosis is unknown, although it is thought to be connected to an environmental or hereditary link.

"Some are genetically predisposed, others could have inhaled a toxin, there are no definite answers," she said.

"The aim of the group is to make people aware of the condition and to show that there is support out there for them and their families."

Regular meetings are being scheduled, she added.

"We will be holding regular meetings for sufferers, their families, GPs and anyone interested in attending," she said.

"The first one will be on August 21st from 8 to 10pm in the Solus Building at ITT. "We had twenty new sufferers who came on Friday and we hope

'I had never even heard of sarcoidosis'

By MARY MORPHY

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Karolien started suffering from sarcoidosis 15 years ago and her health problems intensified in 2007.

Irish Sarcoidosis Support Network which recently launched in Southwest Kerry.

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Marian Geraghty Run 2009



The Marian Geraghty Sarcoidosis Trust Fund held it's annual 10K/5K Run on Sunday 5th July 2009 in the village of Mount Bolus, County Offaly.

This was the 6th year for the 10K run by elite runners from various Harriers clubs across Ireland. This year over thirty competitors from Bedfordshire, Kent, Lichfield, and Oxford came with high expectations. Our locals now have the competitive edge to train, complete and improve their time each year. Particularly the adventurous lads doing the 'three legged' and completing the 10K course in a fairly good time. It was the 2nd year for the 5K run/walk for under 16 runners and for those who prefer a leisurely country stroll.

The famous 'Bed' took part again this year, filled with young village children and pushed by the brave. They completed the course this year at a faster time! Well done to all.

Some very impressive times and individual performances were achieved. We were supported by the Civil Defence who provided two paramedics and the ambulance who followed the runners home safely to the finish.

Whilst everyone completing the race received a medal there were prizes presented to eight categories.



A vast array of refreshments were served in the community hall for everyone during the presentation. Once again a huge amount of work was put into the organization and smooth running of the race so a very 'Big Thanks' to everyone who was involved. Due to the current financial climate, this year it was decided by the committee to charge an entrance fee for those who wished to participate.

Some people made additional donations to the fund which was very much appreciated. I wish to say a special word of thanks to Ed Mezzetti and Patrick and Malcolm Riley who ran the London Marathon on the 26th April. They raised a total of €2500 for ISARC. John Drommey and Zona Keating of the North Laois Trekking Cross Country Club organized an event which raised €1000 for the Marian Geraghty Trust Fund. These events are so important not only to raise funds but to highlight sarcoidosis as a disease which affects thousands of Irish people.

We shall be presenting €5,000 to Dr. Seamas Donnelly to go towards the Sarcoidosis Research Fund at University College Dublin.

