

LIVING WITH SARCOIDOSIS.

It is very difficult in the beginning when you have just been told you have sarcoidosis and in most cases people have never heard of the condition before.

Once you have researched and asked numerous questions of your GP, specialist and other medical personnel you are then in a position to make informed choices about how to manage your disease. You may have the disease but the disease is not you.

Here are a few suggestions that can help make life a little easier for you and your family.

Keep a Diary.

A diary is important and will enable you to keep a record of visits to your GP and specialist; medication record; scan, blood and lung function tests; etc. It will help you record how your day has been ie. good, bad or indifferent. This information is vital to others if you are unwell or if an emergency should occur.

Education.

The first person to tell you about sarcoidosis is your GP or specialist and it is from here onwards that you will need to learn as much as possible about your disease. This knowledge will enable you to have a better understanding of what is happening to your body and how it affects your health. You will need to concentrate on the organ that affects you. This knowledge will also help your family and loved ones be better equipped to support you.

You need to remember that sarcoidosis does not present with the same symptoms in every patient and there is no single treatment plan for all patients.

There are many resources available to you:

- Your GP/consultant/specialist should be your first point of contact if you have any questions.
- The internet - which has made knowledge available to us all. But we need to be careful and selective about what we read. If you do not have a computer at home, your local library or internet cafe can help you access the information on-line.

Sarcoidosis mimics a lot of diseases so you may see more than one consultant in the beginning. It is important that the correct diagnosis is made. Your GP and specialist will oversee your continued care.

Medication.

It is not uncommon for a specialist to tell you to wait for up to 6 weeks or a few months. They may delay treatment until the results of repeated tests are available. They have to consider the possibility that your sarcoid will burn itself out without any treatment. This is one of the mysteries of sarcoidosis. Treatment with steroids (Prednisolone) is only commenced when symptoms dictate it necessary, usually when the symptoms interfere with the activities of daily living ie. breathing, vision and heart activity. The aim of treatment is to slow or suppress the immune system ie. granuloma formation. There are other drugs used in the treatment, Methotrexate, Azathioprine which have been successful and they help reduce the need for high doses of steroids.

Diet.

There is no special diet for sarcoidosis. If you have specific problems such as diabetes, high blood pressure or a high calcium level your doctor will need to advise you.

If you have no restrictions then it is best to focus on a well balanced and nutritious diet.

A healthy weight should be an aim for us all. When taking steroids this can be a concern. It may be necessary to consult your doctor or dietician.

Exercise.

Exercise is very important. Do as much as you can, choose what you can and want to do and gradually increase your exercise programme.

Cramps are one way that the muscles tell the body something is not right. Muscles need regular exercise and proper nutrition.

Attitude.

Aim for a positive attitude - your approach to your health condition will set the tone of your attitude. Humour and faith may play an important part in maintaining a positive attitude.

Some patients may need to make changes to their lifestyle because of sarcoidosis. It is easier to adapt to changes when you understand. Knowledge is power and everyone's best medicine.



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Dear Supporters

A very warm welcome to the eight edition of the ISARC newsletter. The support group meetings continue to be held on a monthly or bimonthly basis have generally had good attendances. The Official Launch of the Enniskillen support group took place in September 2011, this was a great success and of course it is the first Sarcoidosis support group in Northern Ireland. I would like to congratulate Sylvia Armstrong, her family and her hard working committee on their very efficient and professional set up of the group. This was evident with the large and varied attendance at the launch.

The Tralee branch was sad to say goodbye to Karolien Verheyen, who had been the group's facilitator since its launch in 2009. Karolien has returned to her native Belgium and we all wish her every success and happiness for the future. We thank her most sincerely for all her hard work in the setting up of the Tralee group and in maintaining and facilitating the group meetings over the past two years. Joan Lucey, Deirdre Ryan, Patsy and Conor O'Leary have agreed to take responsibility of the group.

The Thurles group is organised by Jutta Leahy and continues to have regular monthly meetings on the last Friday of each month.

The website has been of great benefit to all since it has been upgraded and updated. We had a few teething problems in the first few months but those have now been resolved. We hope to continue to look at ways to improve and would appreciate your help, comments or suggestions on how we can achieve that.

The Marian Geraghty Sarcoidosis Memorial Fun Run/Walk took place on Sunday 3rd July in Mount Bolus, Tullamore, Co. Offaly. This was the 8th Anniversary of the event with over 250 runners and walkers registered for either the 5K or 10K. The good turnout was helped by the glorious weather on the day.

In the past month we have been very fortunate to have been given additional funding by the Irish Lung Foundation. This money will enable us to maintain the groups and set up a much needed support group in Dublin. Without this injection of money the group was in serious danger of ceasing. All personnel work on a voluntary basis but funding is needed to maintain each individual group. Expenses include production of posters, information leaflets, insurance and audited accounts.

We do need your help, in order to be able to maintain the groups, for example to hand out flyers in your area, so that we increase public awareness of this disease across Ireland. I need your personal stories, interesting experiences or helpful suggestions for our newsletters.

My grateful thanks to all who have made a tremendous effort in helping and supporting ISARC

Mary Walters

Mary Walters



Enniskillen Sarcoidosis Support Group Launch.

The Enniskillen Sarcoidosis Support Group began with a start-up meeting in November 2010. Meetings were agreed for the 1st Monday of each month with the exception of the summer period. We aimed to have a guest speaker for each meeting but unfortunately this was not always possible. In the end we opted for talks from the Citizens Advice Bureau, Optician, Pharmacist, Holistic Therapist, Nessie Blair - British Lung Foundation, Mary Walters - ISARC - Tullamore Branch.

A committee was elected in Feb. 2011 and it was also agreed to start fund-raising events by the group. Many of our team efforts were very successful and greatly enjoyed by those who participated. For example we had a car boot sale, bag packing, quiz sheets, table quiz, sponsored cycle by NI Power, card making and there were many kind donations.

We held our launch in the Killyhevlin Hotel, Enniskillen in September 2011 to raise much needed awareness of this disease in Northern Ireland. We were very fortunate to have Professor Seamas Donnelly, Respiratory Specialist, of St. Vincent's University Hospital Dublin and Medical Advisor to ISARC as our guest speaker. Mary Walters, cofounder of the Irish Sarcoidosis Support Network was also in attendance. We were honoured that Mr. Edwin Poots, Health Minister, Arlene Forster, MLA and Counsellor Raymond Farrell were all present and our local respiratory consultant, Dr. McManus from the Erne Hospital was very supportive of the project. The local daily papers did a feature on the launch which generated a great response. Enquiries were received from all over Northern Ireland from people willing to travel to Enniskillen for the meetings.

Our local councillor was approached to discuss the possibility of making the politicians in Stormont aware of our group, with the result that the health committee have now given us an invitation to go for an informal meeting. We would like to get a campaign in place to get a free eye test for sarcoidosis sufferers in the future. We now also have a group constitution in place.

We are trying to secure funding from our local council by means of a seeding grant. We are applying to become a Registered Charity. When this happens it will make it easier to secure funding. We are also looking at setting up a web page within www.fermanagh.info and hope to have that running shortly.

We have already secured a Community Dietician and a Psychologist for patients who have respiratory diseases as guest speakers for our 2012 events calendar.

WHSC (Western Health and Social Care Trust) held a health fair in the Killyhevlin Hotel recently and Enniskillen Sarcoidosis Support Group were approached and asked to put up a stand which led to meeting many new contacts. We are currently planning a short course on "Managing the Challenge" on living with a long term condition in which members can participate.



Attending the launch of the Enniskillen Sarcoidosis Support Group are from left; Wendy Watson, secretary; Kevin Slowey, Vice-Chairman; Jillian Armstrong, founder; Sylvia Armstrong, Chairman; Professor Seamus Donnelly, guest speaker and Mary Walters, Tullamore.

The Marian Geraghty

10K/5K Road Race

3th July 2011 in Mount Bolus, County Offaly



This was the 8th year for the 10K Run and over the years it has just got bigger and bigger. We had tremendous support and participation by runners from various athletic clubs across Ireland and approximately twenty competitors from clubs in the United Kingdom, who came with high hopes and great expectations. Our locals though, had the competitive edge to train and improve their time once again. We appreciate their participation and support over the years.



This was our 4th year for the 5K Run/Walk for the elite under sixteen runners and for those who preferred a leisurely country stroll. Some very impressive times and individual performances were also achieved this year.

We were supported by the Civil Defence, with an ambulance and paramedics who kept a watchful eye on the runners all the way to the finish line.

Everyone who completed the race received a medal and there were prizes presented to the winners of the eight categories. There was a vast selection of refreshments served in the community hall for all present during the presentation of the prizes.

A huge amount of work is undertaken each year in organising this event and I would like to take this opportunity to thank each and everyone who was involved. I am delighted to be able to report that this year we raised in the region of €3,000. This money will be presented to ISARC to enable them to maintain the support groups and increase public awareness in Ireland.

For those of you who would like to participate or help in any way we would welcome your support. You can contact me on annriley1@yahoo.co.uk or call Brackens' Shop on 057 9354790

Ensure that Sunday 1st July 2012 is a date for your diary. Come along to Mount Bolus for a real family day out and support people who suffer from Sarcoidosis.

Registration/Sponsorship cards will be available from Brackens' Shop, Mount Bolus, Tel No.057 9354790 and Beehive Pubic House, Mount Bolus, Tel No.057 9354615.

