

www.isarc.ie

We are delighted to announce the launch of www.isarc.ie our revamped online presence which allows us to be in constant contact with our members. The new website is informative and easy to use. You can register and contribute to discussions which are invaluable in connecting people and information. There is also a donations facility which allows our patrons to contribute much appreciated funds. Our gallery and publications sections help create a sense of community among members and supporters.



Some Dates for Your Diary

Tullamore Branch of ISARC

Meetings are held on the 1st Wednesday of every month. Please visit [www.isarc](http://www.isarc.ie) for more information.



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Dear Supporters

A very warm welcome to the seventh edition of the ISARC newsletter. We are delighted with the positive feedback to our newsletters which have proven a great way to keep people informed, especially for those who are unable to attend support group meetings or who do not have access to the internet.

I have been involved in a number of events and will update you on what has been happening in the past year. In March the third support group was set up in Thurles and Jutta Leahy who is the facilitator there has been holding regular monthly meetings on the 3rd Thursday of each month. She is doing very well and we wish her and the group all the very best.

In May/August we had two startup meetings with a view to doing a launch of a support group in Dublin. Professor Seamas Donnelly attended both meetings and did a presentation at the second meeting on Sarcoidosis followed by an open forum. We had a very good turn out and we hope to do an official launch possibly in the spring. The first meeting was held in Jurys Inn, Ballsbridge on May 20th and our second meeting was at the RTE Sports and Social Club. On Monday 1st November we had our first support group meeting in Enniskillen. Sylvia Armstrong is the facilitator of this group. There was an excellent turn out for the first meeting and the group have arranged a second meeting in December. Sylvia plans to have regular monthly meetings on the first Monday of each month and again we wish her and all the very best of success. The Tullamore and Tralee support groups continue to have regular monthly and bi-monthly meetings respectively.

I am so pleased that the web site has been upgraded and I am sure you will all agree that there is a vast improvement in the information provided. It is much more user-friendly and there is an opportunity to interact with people who have Sarcoidosis. Professor Seamas Donnelly, John Leahy and I were actively involved in deciding on the content of the new website. I would like to personally acknowledge and thank John Leahy for all his hard work and commitment in getting it all together in the last few months. I am aware that we have had a few teething problems but we are sorting them out as we go along. The great advantage with the new site setup is that it can be easily updated.

This year with the current financial crisis, fundraising has been very limited. We would like to thank Mary Smith, Daingean; Bridie Byrne, Ballafin and Maureen Collins for their continued efforts in fund raising for ISARC and more importantly in increasing public awareness of this very unpredictable disease.

A lot more work needs to be done and as I have indicated before we need more people involved in the groups to help. There is a real need to expand the number of support groups throughout Ireland but we need key people who are willing to spend two-three hours per month.

On behalf of all at ISARC I would like to take this opportunity to congratulate Professor Seamas Donnelly on his recent achievements and we all wish him continued success in the future. We acknowledge his commitment to ISARC and his endeavours to find a cause and cure for sarcoidosis.

We would also like to wish Dr Aidan O'Brien the very best of success in his new post as Respiratory Consultant in Limerick University Hospital and to welcome Dr Mark Seedy to the Midlands. I am delighted to inform you all that we are now a Registered Charity.

We were very fortunate to have two guest speakers in the past six months, Barbara O'Connell, a pharmacist, who gave a talk on drugs used in the treatment of Sarcoidosis. This was an excellent talk and everyone had the opportunity to ask Barbara questions on all aspects of the treatments available for Sarcoidosis.

Also, Fidelma Feely Kiernon who gave a very detailed talk on Social welfare benefits, we had an extended question and answer session that evening, which was very helpful. I know that Fidelma has advised a lot of people over the year who had financial worries and work related problems.

Mary Walters

Mary Walters



Drugs used in the Treatment of Sarcoidosis

As Sarcoidosis is a disease which is thought to occur as a result of an abnormal immune response, the drugs used to treat it try and counteract this abnormal response. The first line of treatment is corticosteroids.

Corticosteroids

In the body cortisol is naturally produced by the adrenal gland and they are involved in many body functions including immune response and regulation of inflammation.

When synthetic steroids are given at doses higher than the body naturally produce, they can suppress the immune response. Corticosteroids are available:

Orally

- In doses of up to 30mg per day in a single dose after breakfast. (Any higher dose can be split between breakfast and lunch).
- Doses must be reduced very slowly as the body needs to get used to producing natural steroid itself to replace the drug.

Inhaled

For regular use, but at a much lower dose. It is very important to use the inhaler properly and to avoid thrush and sore throat or hoarseness. Always rinse the mouth or brush the teeth after use or use the spacer if appropriate.

Topical

Creams should be used sparingly, they come in varying strength. Eye drops should only be used in small amounts. It is important to take particular care with how long a cream or eye drop stays fresh once it has been opened.

Injections

Much quicker way of getting high dose steroids into the system and they have a total body effect.

Side Effects

- **INFECTION:** As the immune system is suppressed and one is more susceptible to infection in particular Chicken Pox and Shingles
- **OSTEOPOROSIS:** Steroids cause a loss of bone density and a drug, known as, Biphosphate should be taken each week or monthly to counteract this. Exercise and diet can also help. But care needs to be taken with calcium supplements if the patient has high calcium levels.
- **INSULIN PRODUCTION:** can be affected by steroids in the body but this would usually happen in the first six weeks of treatment.
- **STOMACH DISTURBANCES:** Ulcers can occur when on steroids so a stomach protector should be prescribed for example, Protium, Zoton or Zantac.
- **STOMACH DISTURBANCES**
 - Psychiatric (mood changes) - Cushing syndrome/reversible
 - Raised Blood Pressure - Fluid Retention
 - Weight Gain - False appetite.

Immunosuppressants

These can be used in a variety of conditions where the body's own immune system needs to be suppressed. When used with corticosteroids they allow for a lesser dose of steroid to be used and therefore reduce steroid side effects and also prolong the time that steroid can be used.

Azathioprine

The benefits of Azathioprine may only be seen after several weeks of use and like steroids you should never stop treatment suddenly.

Side Effects

There are serious side effects associated with Azathioprine, the most serious being bone marrow suppression and blood tests should be done weekly to monitor this when therapy starts and regularly after the first few months of treatment. Signs of bone marrow suppression are as follows and must be reported immediately to the doctor:

- Bleeding/Bruising
- Infection/Fever
- Kidney Problems
- Skin Reactions
- Gastric Pain/upset
- General Pain
- Jaundice

Also people on Azathioprine are more at risk of skin tumours, therefore, they should use sunscreens. Hair loss can also occur but this can resolve itself. It must not be over handled by pregnant women.

Methotrexate

- Another immunosuppressant that can alter the growth of cells and reduce inflammation
- It is only ever given as a once weekly dose either orally or by injection.
- Folic acid must be taken weekly to limit the side effects.
- It must never be taken by pregnant women or handled by pregnant women.
- Full blood tests must be carried out before starting and every week until treatment is well established as well as Liver and kidney function tests.
- Methotrexate allows a lesser dose of steroids to be used or it can be used on its own.

Side Effects

- Bone marrow depression
- Liver problems
- Gastrointestinal upset.
- Sore mouth, constipation, skin rash etc
- Pregnancy must be avoided during treatment and after for up to six months and this applies to men as well as women. Methotrexate affects the sperm and egg production.

Hydroxychloroquine

- Not known how it is effective but seems to be good in patients who have skin problems or high calcium levels.
- Like other medications it may take weeks to see a benefit.
- Before starting treatment, eye, kidney and liver function tests are carried out to monitor any deterioration while on treatment.

Side Effects

- Skin rash
- Diarrhoea
- Retinal (eye) toxicity can be a problem.
- Other Drugs used in the Treatment of Sarcoidosis

Thalidomide

This is an immunomodulatory drug with an anti-inflammatory action. This medication has had very negative press in the past, as it can cause very severe birth defects.

Women of child bearing age must use contraception a month before starting, during and a month after finishing the medication. The oral contraceptive pill and the coil would not be sufficient, condoms should also be used as the drug is found in male sperm. Men should use condoms while taking the medication and up to a week after finishing it, especially if their partner is pregnant or of child bearing age. A pregnancy test will be performed before each new prescription is written and pharmacists must get authorization to dispense it which has to be renewed every two years.

Side Effects

Thalidomide can cause drowsiness, constipation, peripheral neuropathy, vomiting or dry mouth. There is a high risk of Thromboembolism, clots for at least the first five months of treatment. It can also cause liver and kidney problems.

Cytokine Modulators

These are medications that would only be used under very strict consultant led supervision. They are polypeptides (proteins) which are produced by the body and they have a natural immunomodulatory effect.

These medications would only be used when other treatments have failed.

- Adalimumab
- Etanercept
- Levtolizumab Pegol
- Infliximab

All these inhibit the activity of tumour necrosis factor alpha (TNF-antagonist) and all can be used on their own or in conjunction with Methotrexate.

Side Effects

They are associated with severe side effects Infections: which includes reactivation of TB, Hepatitis B, Septicaemia. Nausea, Fever, Depression, Heart failure and many very serious blood disorders. When these medications work they are life changing. They work so well but patients must make a very informed decision before starting them.

Over the counter medicines

- Always inform the pharmacist if you are on medication before purchasing any drugs to avoid interactions.
- All medical expenses can be claimed back against tax on Med 1 Form.
- Although patients may not qualify for a Medical Card, they may qualify for a GP Visit Card which has a larger threshold for earning. You can obtain a form from the local health office.
- No family should pay more than €120 per month on medication.
- To ensure continuity of treatment, phone the pharmacy the day before you are due to collect your prescription, to make sure all your medications are in stock.

Images From Marian Geraghty Run 2010

