



SJOGRENS  
NZ

**SJOGREN'S**

**SYNDROME**

**SOCIETY OF NEW ZEALAND INCORPORATED**

**December, 2009**

CHRISTMAS GREETINGS



### **Workshop**

We have just completed a wonderful workshop held at the Ernest and Marion Davis Library. This wonderful old building has seen many things over the years and this meeting seemed to reflect a turning point in Sjogren's support.

The meeting got off to a false start when one of our guest speakers, Peter Mackley, from Essology, could not be contacted. Peter has been organizing dental materials that have proven very useful in terms of preventing tooth decay.

**Tooth decay** is of great importance to Sjogren's patients as those with teeth can face an expensive time when decay is allowed to run wild. These materials, which I have talked about many times, cover two phases in tooth decay. The first is to alter the biofilm which is a layer of bacteria in the mouth which is naturally present on gums and teeth. This makes up part of the plaque found on teeth which tends to form in people with a more acidic biofilm which encourages types of bacteria that make acids in their waste. Obviously to constantly bathe the teeth in acid will erode the calcified structure. People with more alkaline biofilm tend to make more calculus or 'tartar'.

There are a few internal, dietary and hygiene influences. If you have acid reflux which causes heartburn or some metabolic problems which increase body acidity the mouth will have an increased application of acid.

Poor oral hygiene with ineffective cleaning and snacking in-between meals gives the acid-loving bacteria lots of substrate to convert into acid worsening tooth decay. Tooth decay can be slowed by making plaque very alkaline for short periods with a mouthwash with a high pH which is very alkaline, like caustic soda or baking soda. The product system from Essology has a pH of 10.3, and contains caustic soda. It has been made safe, by being buffered meaning only tiny amounts of caustic soda come out of the mouthwash at any given time - much too small an amount to burn you. When that is used up, then more is released. When most of the acid bacteria have fled or died, then you change mouthwashes. The second phase is to use Xylitol. This is wood-sugar and the bacteria can ingest it but not digest it. This kills any survivors.

Peter has noted an increase in enquiries from the New Zealand Sjogren's Syndrome group. Chewing gum containing Xylitol or using Xylitol as a sugar substitute at home is very helpful to prevent tooth decay.

The main event followed and we were treated to the most wonderful treatise about **Dr Christine Rushton's recent trip to Brest, France for the 10<sup>th</sup> World Congress in Sjogren's Syndrome and the first International Meeting of Sjogrens Syndrome Associations.**

Our thanks has to go to Christine. She is a Mum, a part-time GP and has Sjogren's Syndrome. On top of this she personally paid to go to the Congress with some support from the French. This is of immense value to us all, as you will hopefully learn.

The congress was essentially divided into two major parts. Patient's meetings and doctor's research presentations.

The French Sjogren's Syndrome Society have great support from those in the French academic circles and from those who have been treating and diagnosing which makes for a great link between the medications and the end users. The French medical team running the conference contributed significantly financially to our attendance there, and were very involved with the patient groups also. Close involvement of doctors and patients was also reflected in the Japanese SS Association team which included a Rheumatologist and several of his patients.

Dr Rushton has collated all of this material into an extensive power point presentation. This Power point will become useful in many ways and it is intended be used for education.

**Copies of the power point can be forwarded to your GP on request.** Health providers have little idea about Sjogren's and that means there are newly diagnosed people arriving all the time who do not know what to do, where to seek help and those who are the obvious sources of help are ill informed. We, as a group, are charged with this essential promotion. The time really has arrived that each and every one of us, is obliged to tell some one.

Dr Rushton's presentation covered the Brest meetings with information on Sjogren's Syndrome including:

- SS genes and influences on these genes by viruses and toxins which define how and when the genes express
- An update on the disease process in various parts of the body
- Treatment options and new advances in diagnosis and treatments

There are many genuinely exciting things happening. For instance, there is now clear evidence that there are two main types of SS. **The traditional Primary Sjogren's syndrome and a new subtype called IgG4 Disease**, which was officially recognised this year. There are differences in the tissues IgG4 Disease involves. The salivary glands themselves are swollen but much less destroyed and this can be seen in biopsies of the salivary glands of the lip. Also IgG4 Disease occurs equally in men and women, unlike primary Sjogrens, where more than 90% are female. Unlike 'normal' SS, IgG4 Disease is very responsive to Steroids.

The IgG4 has a different pattern of other tissue involvement for instance the pancreas, an organ in the gut controlling insulin with its effects on growth and blood sugar. Kidneys and bile ducts are seriously affected in the IgG4 version of SS.

These sometimes serious complications of IgG4 are fortunately very responsive to Steroids.

**Skin Biopsy** which is positive in about 80% with pSS is a new and relatively accurate test for SS and is very useful when lip biopsies are negative but SS is still likely.

**Medications** too are changing. There is a simpler and probably better form of medication in Rituximab which is currently used in Rheumatoid Arthritis. This is showing real promise particularly when used early in the progress of the disorder. Early use limits tissue damage. Rituximab directly interferes with the B Lymphocytes from your immune system which are misdirected and attacking your own body tissues. There have been many links between other disorders and autoimmune disorders. Lupus and Rheumatoid Arthritis are strongly associated with SS patients (25% have SS).

In Secondary Sjogren's, SS is not the 'main' disease but is intrinsically the secondary disorder. Secondary SS involves 3% of the population. In New Zealand this means about 12,000 people will have the "double whammy" of SS and another autoimmune disorder.

New understanding of the manner of expression of autoimmune disorders was detailed. There is no specific gene but a number of genes involved in the autoimmune family of disorders.

**Gene expression** can be altered by stressors, and depending upon the stressor, it will be expressed as Sjogren's, Arthritis, and Lupus etc. Interestingly these expressions seem not to happen if you have been exposed to Malaria.

Stressors are the trigger for Auto-immune diseases. These stressors can be internal or external. Internal are things such as environmental toxins and toxins made in the body as the result of other metabolic disturbances. External stressors are personal ones. Examples are death of a family member, divorces and similar crises that tax the whole body. These stressors are well known and have a scale of impact.

Viruses too have an integral role in the process. Viruses can enter the cell and break the DNA and then alter the chemical composition in a process called Methylation. This adds a Methyl group onto the fragments left over. This altered bit of DNA will have a different effect on the whole "gene" and its action. This can be glimpsed in the treatment of Hepatitis. This uses Interferon, a viral-like vaccine. Using this can induce SLE (Lupus) or Sjogren's to develop.

Bacteria too are implicated. The bacteria which causes stomach ulcers is H.Pylori. Surprisingly this can flourish in the highly acidic environment of the stomach and alters the lining. H.Pylori bacteria is linked with autoimmune disorders where the bacteria acts as a stressor triggering the genes and also is implicated in MALT cell lymphoma, a stomach cancer with 4% incidence in Primary SS. It has been shown that eating Brussel Sprouts regularly inhibits the bacteria's ability to produce alkali to protect itself and can help control but not eradicate H Pylori. It is 'treated' with a Triple-approach using Losec (omeprazole) to stop the acid production and twin antibiotics to hit the bacteria itself.

I**T**P is an autoimmune problem where platelet cells in the blood are much fewer than normal, which causes bleeding problems as the blood does not clot properly. Research given at the conference shows treating H.Pylori can seemingly increase platelets sometimes back to normal levels. Also Antiphospholipid may be cured by treating H.Pylori which is also an autoimmune disorder where the chemistry of the cell wall, containing phospholipids, is altered and doesn't function properly causing a tendency to form blood clots and is associated with miscarriages.

It seems that there is an entire line of study available to look into reversing that 'switch'. This process of 'expression' will also explain why many have more than one autoimmune disorder... for instance many have Lupus as well as SS.

Resveratrol, which is a food supplement in a concentrated form of the anti oxidant found in red wine and shown to have health benefits including decreasing blood glucose is theoretically useful in autoimmune disease by reversing this switch but no studies are available so we are cautious about its promotion. However, it may be worth a try. If you have already tried this we would be interested in your feedback.

## **Medications**

This formed quite a large part of the discussion. The mainstay of SS in New Zealand has been Pilocarpine. However there are a number of other drugs that show real promise and usefulness;

- 1) Cevimeline when used with Pilocarpine - this benefits 40% of SS.
- 2) Rituximab and Infliximab.
- 3) Etanercept.
- 4) Hydrochloroquine (see Malaria later).

Pilocarpine can be made from eye drops (1mg/ml) and used orally with 2.5mls to 5.0mls per day dripped onto the tongue. People on beta blockers and with heart failure and several other conditions should not use this medication. A doctor needs to consider your current medications and conditions before prescribing this.

There are a number of commonly associated disorders that are real clues to SS on the:

- **Skin:** Vasculitis, which is red (blood-blisters) seen mainly on the legs.
- **Bladder:** Cystitis or bladder wall inflammation.
- **Gut:** MALT lymphoma and coeliac disease and specific forms of pancreatitis.
- **Lungs:** Interstitial lung disease is well recognized in SS. Loss of elasticity making breathing far less effective, as the lungs can not freely expand.
- **Eyes:** This topic was very well covered by Dr Rushton;

There are three components in tears. The bulk of the tears are made in the tear glands situated above and to the side of the eyeball. Mucin (mucous) is made by the Goblet cells on the eye surface and this is supplemented by the oily/waxy secretions of the Meibomian glands. These are hidden on the edge of the eyelids and then there are the lubricators. These oily secretions are made and mix with the tears. This allows an even moisturizing spread of tears. All three are needed to give the best results and SS affects the production of all three but in different ways. Tears are therefore less than ideal as (primary) SS destroys these tear-producing glands.

To combat dry eye, blink more frequently, and use lubricants (moisturizing drops and ointments that should not have preservatives in them). Oils such as Flaxseed and Omega 3 seem to help too. And blocking the tear ducts with plugs or cauterizing. There are numerous medications; one of which Dr Rushton mentioned was Rituximab, which is very effective when used early in the disease as it limits tissue destruction. Non-steroidal drops (Acular) and anti-biotic drops cyclosporine and Doxycycline have a good track record.

## **Dry Mouth:**

The lack of water and lubricants shows up in two ways. First it allows the tissues to become dry and 'sticky' and so more easily damaged. Pain in the soft tissues is common and one very good reason to maintain your teeth, as full dentures can be hopelessly aggravating and best avoided if possible. As the conditions change, the biofilm will too. This can promote acid breakdown of the teeth (decay) as well as loss of supportive gum tissue.

As we all know, repairing teeth is not fun both physically and economically. As a dentist I know the running of an average practice is now close to \$500 per hour. This is reflected in the cost of treatment. A good example is implants. While 90% of single tooth implants survive over 30 years, they are thousands of dollars for a single tooth. This is an expensive solution, so prevention is imperative.

- 1) You can improve your lot by making sure you have a good understanding of the process. Acid kills teeth. Ensure that you brush or rinse after food.
- 2) Don't use 'sugar-filled' water to sip, nor add things such as a drop of lemon juice.
- 3) Fluoride Toothpastes are shown to reduce decay.
- 4) Use Xylitol based chewing gum or the Caries Free program.
- 5) Make sure your dentist has joined SS group and is well versed in SS.
- 6) Liberal use of oral lubricants.
- 7) If you have a denture, take it out at night and softly clean it and store it in an anti-microbial (bleach is good) bath. If you cannot take it out without problems such as snoring, then ask your dentist for a 'spare' and swap them over.
- 8) Ensure that if you have teeth and a high decay rate, you have discussed this with your dentist and develop a good plan so when one tooth is lost, it is not an unexpected disaster. For instance if a tooth is likely to be lost, why spend a lot of money on its restoration? A root filling and a crown will probably cost over \$2,000. Money wasted if that tooth is lost.

While eyes and mouth are well known problems, so are lungs, pancreas, kidneys as well as bladder are involved. This is important as it can be anticipated. If you have SS these organs are likely to be targets. Conversely, involvement of these organs is commonly linked to autoimmune disorders. 28% of people with Interstitial Cystitis, which is inflammation of the bladder wall, will have SS. 4% of people with primary SS have this. It can be checked and the urine sample should show signs of inflammation (blood etc) but no bacteria.

One distressing complication is Vasculitis. This is as if the small surface veins have pinpoint bubbles. Mostly seen on the lower leg, it can be felt as a small bump. A more invasive and widespread version is 'systemic' vasculitis. This can be dangerous even fatal, as it alters many blood vessels and some are critical.

When you have multiple factors the health risks compound. Dr Rushton covered various promising new drugs and new applications for old drugs. This was a presentation packed with information on the very latest research and applications in the clinic and at home.

You can order a copy of this presentation and share it with health professionals such as your GP or Dentist (you may incur a cost).

**The 2<sup>nd</sup> half of the presentation related to the meetings of the representatives of the different countries Sjogrens Syndrome Groups of which there were 12 represented.**

Some of the benefits to come from the "SS Patients" Associations meetings were:

- SSF (from USA) will send their very extensive newsletters by email, to each country.
- An email tree will share information and successes between organization reps.
- A yearbook log of international SS organisations has been prepared and handed out to all those who attended. And an International Collective of SS Organisations began.
- The International Collective is approaching the manufacturer of Evovax to see if this can be made available in other countries.

It is obvious that the other organizations are far more adventurous than us in many ways. Some of this relates to funding and some of it to enthusiasm. There are a few research projects underway for example. Government could be lobbied to get funds for dental care is may be one project that we could take up here.

This wonderful presentation sadly came to an end with the tea break.

**Our South Island Committee member Anne Mackay, from Ashburton** spoke next. She has made contact with her local M.P. who met with Anne and has promised to do what she can to raise the awareness of SS in New Zealand and she has already started. When Anne told her that **Pilocarpine** was being taken off the Pharmac list of subsidized medicines, she called Pharmac and within a short time, it was back on the list. Our thanks to Anne for this!!

Anne encouraged us all to get involved and take action for SS.

### **Where to from here??... Subscriptions**

The meeting then covered the thorny problem of overall direction of the Society and of money. There was a great deal of discussion around the concept of what this society is really about. While there were over 70 people at the workshop, this is only 10% of those in the organization. The coffers are low, but then many people are in this situation. There was a lot of debate. It ranged from the opinion that most people with SS could afford \$1.00 per week. However the opposite view was that many people do struggle to get through each week.

So as a draft I proposed we set **a voluntary subscription of \$40.00 per year**. This will be voluntary and for those who do not have a wage, they may opt for the lesser amount of \$20.00. Following the meeting, the committee met and generally it was suggested that something along these lines be formally adopted and that nobody should ever be denied access to this support and access to information because of finances. This was the basis of the support group as set out from the beginning by Felicity and one I endorse and I feel even those who don't fully support it, acknowledge it.

Moving on. There was a lively discussion of where the newly formed society is and where it should be. Dr Rushton has showed that we are very low-key by comparison with what other organizations around the world are doing. Yes, we are the only organization that doesn't have a subscription. We have only just formed a formal Incorporated Society from a cherished voluntary organization.

This has prevented us from spreading the word about Sjogren's. This means there is about 1,000 of the possibly 20,000 people here in New Zealand that have access to this level of support, leaving 19,000 without that support. This means there has to be a mechanism to spread the word. This should be done through three platforms: Research, GPs and others to be informed, and to give SS people the means to find out for themselves what it is and how to cope with SS.

This requires well-coordinated access to those who organize and do the research. For example, to gain the ear of those who can fund research, they have to know there are a large number of people with this disorder. Then they should know there is an organization that connects and supports them and that there is a real need to ensure that the knowledge of the disease process and its control is promoted. Beyond that there is a need to educate those who diagnose. Dr Rushton has explained to us very clearly that we are well behind the understanding seen in Japan, USA, Canada and of course in France.

Take heart though, as in a competitive vein, there is no organization at all in Australia! However let us not get distracted. Over the next few weeks it is hoped that the mechanisms to start this will be put in place.

**Website.** Our website is now up and running and we would like to acknowledge Mr Philip Coetzee from WebBuilder Ltd for his time and effort to make this work for us.

Contact numbers for 'friends' will be available and a place for 'remedies', drugs and their best use. Many medications and the support medicines are available, for example by prescription. This can include supplements such as Magnesium, Zinc and Vitamins that have been shown to really help general health and quality of life.

The website will also allow you to link to other sites and there are many. In addition we will have available all the information from the international scene. This should allow you to download the relevant pieces of information and you can take that to your doctor. On that note, you should be aware that the average family doctor has many different problems and disorders to look after and they are all advancing with new techniques and medications to consider. So taking clear pieces of information can be helpful for all concerned. However, this does not mean if you have a doctor who is not helping you, don't be too reluctant to talk to them, or if unsuccessful, change your doctor.

There were numerous offers of putting the message in the right ears and hopefully these will prove successful.

**Fundraising.** A few suggestions were made and one that I will explore is to have our logo put on water bottles. There are literally dozens of different bottled waters being sold and as 'dryness' is the one key problem in Sjogren's Syndrome, we all felt that this could be an avenue well disposed to raising our profile. Beyond that there is a possibility that some of the sale proceeds could come back to the Society.

**Friends of the Society.** This is a special section to be created that will allow people to offer help, without having to be on a committee. The very word committee often creates a barrier and it was felt that this was a means that people might be better able to offer help in a more specific way without the issues of being on a committee. If you feel you can help in any way please do not feel that this will not be heard. Who can print the newsletters? We are trying to limit the number of these in preference for emailing. To adapt the words of J. F. Kennedy..."Ask not what your Society can do for you, but what you can do for your Society".

A very generous offer has been made to help in the I.T. department. This will help in forming the email mechanism and converting the old video showing so many helpful hints in a CD form. This person is very well qualified being a 'professor' in the world of I.T. Equally we have had the offer of help from people who are almost 'professional' fundraisers with the promise of more of the same.

I wanted to make a specific comment about Joel Rushton, Dr Rushton's son. He came to the rescue when the projector failed to 'talk' to Dr Rushton's computer and the whole presentation was in jeopardy. Joel also made his mark in the meeting and in the aftermath with various well considered comments. Thank you Joel.

**Fundraising.** There is a wonderful history in New Zealand of fund raising. Why not adapt this with school galas and with other similar forms of fundraising. We can make available information such as the brochures to use in conjunction with these efforts. I am sure that we are only limited by your imagination. If you want to legitimise your effort, get in touch with either Sarah or myself. We cannot give our approval after the fact so ensure you ask before starting any project. Ask your local Lions Rotary and other Service clubs, they are often able to help.

**Road Show.** I will be investigating the prospect of bringing the Sjogren's message to places outside of Auckland. This is simpler and easier than bringing all of the Sjogrens sufferers to Auckland and could be done over a few weeks. This will hopefully be able to take place over the middle of next year. I will try to keep you posted.

So the meeting ended well past the 12.30 deadline and we felt that all who attended were well rewarded for the effort.

**Sarah and I thank the people who sponsored the free goodies, these include;**

- **Xerostom with Saliactive** is a new range of products available from your dentist, pharmacy or on-line for dry mouth, samples have been provided by **Aluro HealthcareNZ**. Aluro HealthcareNZ have also provided the inserted article on Xerostom, a Xerostom information brochure and have supported us with the editing and printing of this newsletter.
- **G.C.** makes a wonderful range of **dental goodies** - NZ distributors are **Henry Schein Shalfoon**.
- **Colgate** too provide dentists with toothpaste that Sarah has made sure found its way into your bags.
- **Wrigley's** provided the chewing gum.

I will keep you informed as this comes together.

Yours truly,

*David Zimmerman*

**Hon President**