

SJOGREN'S SYNDROME
NZ
NEW ZEALAND INC

June 2010

This has been a busy and productive year for the Sjogren's Syndrome Society. Those of you who were at the November workshop will already be aware of the results from Dr Rushton's representation of our Society to the first World Congress on SS held in Brest, France in October 2009.

Dr Rushton's power-point presentation has now been sent out to over 100 Medical Practitioners throughout New Zealand. If your doctor or Dentist has not received a copy and you would like a copy emailed to him or her, please contact Sarah with their details.

Pilocarpine Study

We have attached a copy of the publication of the Pilocarpine study done in Christchurch with Dr's Dennis Thorburn and Polonowita. This was a great study and will add to the bank of information. Pilocarpine is an oral medication that can be used as a mouthwash and was set up to drip into the mouth during sleep via a headgear attachment and a small tube. The attempt to reduce the impact of SS is important not the least because of the high cost of dentistry.

International Society of SS

With the start of the International Society of SS, there has been a great deal of collaboration as we are now party to this exciting growth, particularly in research. This is very active and young researchers are being encouraged to 'donate' their research to the French SS (copies of the two selected young students biography is attached with this newsletter). American and Japanese researchers are also very active with many projects underway and well supported. I wonder what we could manage here in NZ if only we could get that level of support. Perhaps a word in the right ear?

There has been a great deal of writing and email messaging between us and the French Sjogren's Society. This connection has allowed us to access many SS sites around the world and Sarah has printed many pages of material for me to go over.

These sites are generally confidential and locked. Access links have been given to us which is one of the benefits of the World SS group.

There is a vast pool of information and I seek the help of one volunteer member to screen this for relevant information. If there is such a soul, it might be timely to get the best of this information into a newsletter.

Membership

This brings me to the website and the benefits of membership. Because there is a great deal of interest generated by the website and the information contained in it, we feel that to have access, other than the basic information, people need to become a member and then they would have access to a password. Many people call or email our office; Sarah spends much of her time sending out information packs, replying to emails and answering questions only to find the enquirer hasn't returned the membership application form and is not heard from again.

Our website is now fully funded and maintained by membership fees. To ensure that nobody is denied access to essential material, this will be left on the public part of the revised website. For those who have become a member and probably sent a donation, there will be a lot more at the click of a mouse (or is that a squeak). Further to this, we are looking long term with a view of encouraging Medical Practitioners to sign into our secure area for research material and information.

Support Groups

This is a relatively new thing for SS. Small groups are springing up in places all over New Zealand and the most recent is a New Plymouth group started by Judy Eva, this is very encouraging and we thank Judy for organizing this and wish her and the group great success. If you want to start a 'local' group or if you live in the New Plymouth area and want to contact Judy, please touch base with Sarah.

"Little Voices"

This was borrowed from Moisture Seekers.

"Little Voices" Fight a BIG Disease

Little Voices was started in 2009 by Ben – a young boy from Phoenix, Arizona who wanted to help increase awareness of Sjögren's Syndrome. His grandmother had Sjögren's and Ben wanted to have more people understand this disease. So together with others, Ben started Little Voices which is now a group of young people from across America joined together with the purpose of increasing awareness of Sjögren's syndrome. Each little voice is helping to raise awareness in their community about Sjögren's syndrome. Some are organizing fundraisers while others are handing out information. Each little voice is making a difference in their own way! Become a part of the driving forces behind Little Voices.

**"Together
even little
voices can
make a big
difference!"**

World Sjogren's Day

Some of you will have grandchildren at school and SS NZ feel it is a great project for celebrating "World Sjogren's Day" on Henrik Sjogren's birthday, July 23. If we all join together and use this special day every year as a time to raise awareness around the world for Sjogren's, we can surely have an amazing impact!"

Remember there are an estimated 20,000 SS in New Zealand and only 1,000 or so diagnosed and this brings us to a really important part of the problem.

Creating a good doctor-patient relationship.

Doctors and others such as dentists, this begins with you. First you should have a reasonable understanding of the disorder and certainly how it impacts upon people. While it is easy to see a dry, red eye or decaying teeth, what is more difficult to appreciate is the fatigue and the associated health and social problems that go with it. Doctors, please learn not to interrupt your patient. This is something many patients complain of. We all recognize what time can mean to a frantically busy health practitioner. They often find time pressures don't allow unlimited time.

Here is a good lesson for all people involved. Encourage your patient to talk about how they are feeling, both physically and emotionally.

Facilitate a multi-disciplinary approach. Where a partner may not understand the fatigue, you may need help in the form of a counselor. Chronic Fatigue brings depression for many and this too may require a specialist's help to give the SS patient a 'tool bag' of things to help them through the day. When you get up every day and feel totally exhausted, but nobody can see the physical reason, there is little empathy or support and this is challenging indeed. Your support or comment can encourage those around a SS patient, to pay a little more attention to the comments made.

Dentists, talk to your SS patients, advise them that SS cannot (at least not yet) be cured. They have to carefully plan this with you as their guide. They will always have an elevated decay rate; they will never have a 'healthy mouth'. You have to employ techniques such as Caries Free and Aluro HealthcareNZ have "Clinpro Tooth Crème" an Anti-Cavity Paste with functionalised Tri-Calcium Phosphate. Aluro also carry a good range of products including Xerostom for dry mouth which are suitable for your SS patient. Your 'GC' representative will also show you a good range of products suitable for SS patients. NO sugar or carbohydrate in sipping drinks, just water and your SS patient will also have a wealth of information if you talk to them.

Ensure that you understand the medium and long term plans as root fillings, crowns and implants will always have to be on the 'shopping list' and the costs are equally real. Many SS are elderly and have chronic fatigue. Most are not able to have full-time employment so funds are stretched. Full dentures are rarely an answer. The dry mouth makes the soft tissues fragile and vulnerable.

Doctors should be aware of the latest drugs and support methods available. There is a great deal of information available on the website. We can send you the Powerpoint presentation if you email sarah@sjogrensnewzealand.co.nz. Many patients have phoned us in tears of relief after many years, often more than a decade, to tell us they have been diagnosed with SS. The not-knowing and often being thought of as malingering must be very testing indeed. There will always be doubts when there is no diagnosis.

Make sure that you give as much information as possible and allow the patient to sift through it. Where they have access to the Internet, steer them to appropriate sites.

If you don't know or are unsure about medications or self-help techniques that every SS person develops, say so, then go and find out more on this. We are happy to help this process wherever possible and within our limitations. Lack of interest is the most common adverse criticism made about doctors to us. People with SS are diverse and have even more diverse presentations. Think about your responses.

New Therapeutics

A recent meeting highlighted new data on two B-cell targeted biologics in SLE; Benlysta (Belimumab, formerly Lymphostat B), discussed a trial and a subset of SLE showed benefits.

Epratuzumab, made by Immunomedics for treating Non-Hodgkin's Lymphoma, has shown promising results. Its primary function is to act as an antibody on the surface of B-cells and reduce proliferation.

Ritixumab a chimeric anti CD-20 monoclonal antibody in RA and again in Non Hodgkin's by depleting malignant B-cells.

Dacryodentides or Lacrymal Gland inflammation was first described as Sjogren's and later as Secondary SS, which is now superseded.

NOD mouse studies show there is a genetic predisposition for sialodentist and Dacryodentides.

In short this is Genetically "permissive" which means your genes allow SS to start. Obviously some people never develop autoimmune disorders. Environmental factors are "decisive" in terms of germ-expression. This means they direct the mechanism towards the variety of autoimmune disorder you 'get'. Triggers include extended stressful periods such as illness or death, particularly of family and children, or social problems such as divorce and redundancy.

Mast cells have not been proven to play a role, but are seen in vast numbers, so probably do have a role in SS. Mast cells contain histamine and can be seen in action where you get a raised area around a scratch. This is part of your protective mechanisms, but here it's in an unhelpful context.

Exocrine dysfunction may result from defective autonomic neurotransmitter receptor signaling.

The amount of material is now becoming massive and doubtless there will be some real break through, at least to be able to restrict progress significantly, if not a cure.

Dr. Rushton's power point shows the latest approach to understanding. Sjogren's is a two-variant genetically linked disorder. Typical of all autoimmune disorders, there is a genetic predisposition and depending on environmental factors, there will be differences in how the autoimmune disorder presents. Some with SLE, others R.A. Secondary SS is a little unique in that it seems to need a partner, whereas Primary seems to stand-alone. Sometimes this partner is not openly expressed but remains passive and behind the scenes.

Medications:

Artificial Tears

There are a few examples of these but the central theme is not to have preservatives. This then limits shelf life of the medication but does not carry the problems of the preservatives and can add to the problem instead of helping.

The other medications are discussed already above. Ritixumab certainly carries some clinical promise based on the information we have seen so far.

As mentioned above, July sees international Sjogren's Day. In 1933, the Swedish Ophthalmologist, Henrik Sjogren first described the disorder, albeit in minimal terms and now his description is accepted as "secondary SS". Later this description was expanded.

With about 20,000 in New Zealand, there will be about 5 patients in every doctor's practice and about triple that number in every dentist's practice.

These are not easy issues to deal with clinically, as there are many medications and allergies that mimic the optic symptoms and poor oral hygiene, particularly in some prone people which will give an elevated decay rate. What used to be accepted as the "gold standard" of diagnosis now has been shown to be flawed. There are distinctly 2 versions of SS. The second version is more frequent in males, but common enough in women to be of concern in terms of diagnosis. This version does not show up in lip biopsy. So many people doubtless have suffered a lip biopsy only to have a negative result and be told they don't have SS. I might offer a pragmatic approach... if it looks like a horse, has 4 legs, eats hay and whinnies, the name doesn't matter... it's a horse and treat it accordingly as most treatment is symptomatic.

Last year we asked people to respond regarding how they were 'diagnosed'. While often diagnosis was a long-winded affair, those that replied almost universally said it was by a specialist and by that I take it to be a Rheumatologist. What we didn't ask was how many have figured it out for themselves, i.e. they have never been officially diagnosed.

Dr Rushton has written a very concise "DIAGNOSIS OF SJOGREN'S SYNDROME". This is a single A4 sheet and even I can follow it. The first line says...

"Sjogren's Syndrome is often diagnosed late in the process which means people with Sjogren's often suffer for years before diagnosis."

This is so often the case.

It sets out who might diagnose this for you and then goes on to classic symptoms and then into testing starting with antibody tests as this will show the antibodies that may attack the B-cell surface as mentioned above.

Thyroid, eye and mouth tests are all mentioned, as are the various x-ray techniques and of course lip biopsy, which does retain a backup place. This is a clear, concise single sheet of paper that should be in every Doctor's and Dentist's and certainly every Rheumatologist's drawer.

We have certainly moved a long way from a couple of drugs and lots of home remedies. This is a positive and exciting time in the Sjogren's Syndrome world.

World SS day. July 23rd

I have written to TV3 and TV1, and contacted radio stations and the NZ Herald. Hopefully we can raise the profile somewhat and individuals; even if you are a friend or family member of someone with SS, you can help make more people aware. Get the facts right and ensure that people know what it is like to be saddled with this on a daily basis. Few people realize that you can't do simple things like eat cheese and crackers. Stories like this translate this into meaningful terms. SS is real and intrudes into at least 20,000 lives on a daily basis right here in New Zealand.

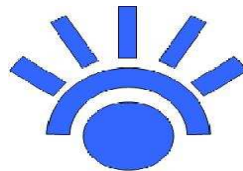
Road Show

While our resources are very limited, we can organize visits to centers within a day's drive of Auckland and we are happy to do this if you can get a group together. If you have a group of Doctors who would like me to talk to them, please contact me: david@tfdental.co.nz.

Finally, we would like to acknowledge our loyal supporters, many of whom have Sjogren's and yet still find the time to help in some way. Your encouraging cards and letters with your donations are always welcome and treasured. We also wish to thank Philip Coetzee of Webbuilder NZ, Aluro HealthcareNZ Ltd and our G.C. Representatives for their generous time and support, without such support this would not be possible.

Keep well and enjoy each day as completely as you are able to.

Best wishes
David Zimmerman
Hon President
Sjogren's Syndrome New Zealand



SJOGRENS

NZ

WORKSHOP 2010

The 2010 Workshop which will be hosted by Aluro HealthcareNZ Ltd, will be held on the 9th October, our flyer will be included with this newsletter. Also included is Dr Rushton's Medical report and the Pilocarpine Study.

We are accepting applications for active Committee Members. If you have good administration skills or you are a great people person with spare time on your hands, and feel you would like to contribute your time to raising the profile on Sjogren's Syndrome as an active Committee Member, please contact sarah@sjogrensnewzealand.co.nz