

## 2ND NATIONAL CONFERENCE SUMMARY

WOLLONGONG 10 - 12 OCTOBER, 2016

The Association's 2nd National Conference was hugely successful with almost 90 patients and carers enjoying the beachside location of the Novotel North Beach hotel in Wollongong.

The speakers were outstanding. The topics ranged across medical information on Myositis and autoimmune diseases, review of global research, exercise and falls prevention, swallowing issues, disability equipment, financial planning, disability employment, rehabilitation for chronic diseases, and issues facing carers.

Significantly, the Association obtained generous donations or grants from sponsors, CSL Behring, Novartis Pharmaceuticals, Veolia Mulwaree Trust, Bendigo Bank, Liquidity Independent Advisors, Destination Wollongong, Centennial Vineyards, Silos Estate, Pizzini Estate, Coolangatta Estate and Two Figs winery. The assistance provided by the sponsors made it possible to support keynote medico speakers from Australia and the USA.

### **Prof Dana Ascherman**

Bob Goldberg of The Myositis Association in the USA arranged for Dr Dana Ascherman, Associate Professor of Medicine from the University of Miami to join us. Dr Ascherman has been involved in research and treatment of Myositis and the overlap with interstitial lung disease for the last 20 years. He generously spent invaluable time with Polymyositis and Dermatomyositis patients in an informal session on the first afternoon answering wide ranging questions.

Some of the points noted by Dr. Ascherman:

- Don't be a slave to CK levels because the disease may be active despite having a normal CK reading;
- Overlap symptoms of other autoimmune diseases are common with Myositis. It is not uncommon to see a Myositis component (particularly PM and DM) with scleroderma, Sjrogrens disease and lupus;
- When taking immune suppressing drugs such as cortisone and methotrexate, azothioprine, it's recommended to keep cancer screenings - skin, breast, colon, etc up to date;
- Stem cell treatment is not a realistic option at this time but may be in years to come;
- Appropriately tailored exercise is now known to be important not just to maintain function but also as being beneficial in slowing down progression of disease;
- Accompanying lung disease needs aggressive management - high resolution CT scan to ascertain extent of damage (chest X-rays do not disclose sufficient information), and treatment options to be discussed with medical specialists include high dose steroids, Mycophenolate (CellCept) and/or Rituximab.

The next morning Dr. Ascherman was the keynote speaker discussing "How Far Have We Come?" His presentation included a brief review of research across the globe since the first reported incidence of Myositis in 1887.

- 1887 - first case of DM/PM

- 1930 - Gottron describes classic rash in DM
- 1954 - first major English case of Idiopathic inflammatory myopathy
- 1971 - description of IBM
- 1974 - Bohan and Peter develop Criteria for PM/DM (being revised presently)
- 1995 - Griggs criteria for IBM

He then discussed some of the work which is underway to try to refine the understanding of Myositis using Biomarkers. A biomarker is a characteristic that is objectively measured and evaluated as an indication of normal biological processes, pathogenic processes or pharmacologic responses to therapeutic intervention. The current Myositis biomarkers are:

- objective muscle strength testing
- study of muscles enzymes CK, Aldolase, AST/ALJ (but these are imperfect)
- inflammatory markers ESR, CRP (but these are unhelpful)
- antibodies Jo-1 (present in some forms of Myositis)

To accurately diagnose and treat Myositis, more biomarkers are needed eg

- Disease subset specific biomarkers i.e. DM,PM,IBM,JDM
- Organ specific biomarkers
- Activity specific biomarkers

Dr Ascherman explained that research is being undertaken in Sweden, Japan, Israel, and USA, which is expanding the array of biomarkers or tools available and improving the knowledge of the workings of Myositis diseases, particularly in the field of auto-antibodies. The research is moving forward to using the auto-antibodies to identify as subtypes of the disease eg muscle and lung or muscle and arthritis.

He also explained that the therapeutic tools have also expanded beyond steroids and immune suppressants to include exercise, blood products such as IVIG, and biologic agents such as Rituximab and Acrimonol.

Dr. Ascherman predicted that in the future there will be improvements in:

- Pathogenesis - gene expression profiling leading to identifying novel therapeutic targets
- Diagnosis - PET scans/CT scans for disease activity and malignancies rather than relying on biopsies
- Management - anti-autobodies and cell based therapies

To have one of the world's leading researchers and practitioners in Myositis, address our group and provide insights into the work being undertaken globally to improve knowledge of, diagnosis and treatment of our complex set of diseases was very special.

### **Prof Alan Sturgess**

Our patron, Prof Sturgess is a Clinical Associate Professor at the University of NSW and head of Rheumatology at St George Hospital. He followed with an address to generally explain the function of the Immune System and why our immune system makes mistakes. He

explained that it seems the immune system fails either by not being able to rid itself of bad cells or for some reason it loses control over bad cells.

Autoimmune diseases are common and generally divided into;

- organ specific diseases eg skin, muscle, thyroid, or
- multisystem diseases eg lupus

A family history is relevant but can be confusing. It is more likely to point to a tendency to autoimmune disease rather than certainty.

Treatment of Auto-Immune disease is difficult because it is not yet known how to reverse the immune system. Drug treatments are directed at trying to suppress the immune system but not to such an extent as to lose the immune system. This has led to an array of drugs such as cortisone, methotrexate, azothioprine, cyclophosphamide, IVIG, Rituximab.

Another option for treatment of auto immune diseases is to replace the tissue function that has been damaged with the autoimmunity action eg insulin for diabetes, thyroid hormone for hypothyroidism, kidney and pancreas transplants.

At present there's a lot of interest in bowel bacteria and the hygiene hypothesis as being relevant to strengthening immune systems. In the future there will be specific drug therapies for autoimmune diseases.

It's always a pleasure to have Prof Sturgess address our group.

### **Ajay Badakhsh - Independent Home Care Supplies**

Ajay attended from a well established, local supplier of disability equipment (which have partners around the country) and discussed a number of products.

Of particular interest:

- quad walking stick base for any walking stick,
- foldable walking stick for travel,
- single grip portable grab bar for use on tiles
- one touch can opener, bottle opener, jar opener or vegetable peeler,
- under cupboard can opener
- car door wedge which also breaks glass and cuts seat belt,
- car swivel seat,
- back rest with gel pack for heating or cooling,
- a variety of cushions
- Pride Quest fold up scooter \$2795 suitable for use in house, shopping centre - 30kg with battery
- light weight wheelchair 8kg

Ajay mentioned the need to regularly service scooters, walkers and wheelchairs in the same way one would service a car.

He also mentioned the website [www.peak.com](http://www.peak.com) as a good resource of well priced disability equipment.

## **Cathy Brand**

Cathy is a Rheumatology Physiotherapist at St George Hospital who works closely with Prof Sturgess treating people with all forms of Myositis.

Cathy focussed her talk on exercise and falls prevention. She quoted the scary figure of 30% of people over 65 fall multiple times. in the case of IBM the risk of falling is approximately 4 times higher than the general population. Cathy also mentioned the figure of \$16,000 being the cost of treating a hip fracture.

Falls are caused by - 40% tripping, 17% loss of balance, 15% slip, 6% weak legs, 7% dizziness, rest unknown,

She identified the risk factors as;

- medical issues - poor reaction time, muscle weakness, vestibular issues
- gait/balance - difficulty with sit to stand, slow stepping, poor balance when reaching
- impaired vision
- being female
- alcohol
- cognitive function
- environmental (poor footwear, spectacles, home hazards - power cords, clutter, rugs)
- risk taking
- aged over 80 - by 80 muscle shrinks in size by 40% and is 50% weaker
- inadequate exercise
- reaction time - increases by 25% from age 20 -60. Fallers have a 20% increase in reaction time to non-fallers.

Exercise can prevent falls by up to 50%. Balance training must be a component of the exercise. Strength training is not as effective for preventing fall but has other benefits. The programs for exercise need to be of a long duration, at least 6 months and be **tailored specifically to the patient.**

The key muscles used in gait are the ankle dorsi flexors to pull the foot up and the plantar flexors to raise the heel.

To take a step, the hip flexors are used to swing the leg through and hip extensors used to raise the leg up. Gluteal muscles in the buttocks are critical for walking.

To rise from a chair or up and down steps, the quads are used and people who fall have 30% less quad strength.

Useful forms of exercise for Myositis patients are;

- balance
- gentle strength eg tai chi
- general fitness - walking

- hydro-therapy

Exercise is considered safe for Myositis patients, even during flare-ups of the disease provided it is tailored for each patient. A study in 2014 "New Insights into the Benefits of Exercise for Muscle Health" by L A Munters, Helene Alexanderson and Ingrid Lundberg showed improved muscle performance by endurance and aerobic exercise. Their study advocates slow increase over time and preferably exercising 6 days per week combining 3 days of strength exercise and 3 days of aerobic exercise.

Cathy's guidelines were:

- start small (few repetitions, short time period) and be realistic
- listen to body
- review the effect of exercise
- be consistent
- be mindful of other things eg build up of lactic acid and soreness is normal
- exercise according to goals - increased balance, aerobic capacity, improved flexibility
- exercise should not be painful
- wear good shoes
- keep hydrated
- plan
- check in with GP

The day finished with an informal discussion for IBM patients with **Dr. Merrilee Needham**. A wide range of issues were discussed including the key identifiers of the various forms of Myositis:

- DM - skin rash and finger extensor muscles weakness
- Necrotising Myositis - shoulder muscle atrophy
- PM - shoulder and hip girdle weakness with 8-12 week history of progressive weakness in hips
- IBM - long finger flexor weakness. Inflammation with protein and mitochondrial changes

The true nature of IBM is a puzzle. Merrilee postulated that IBM may be an autoimmune disease at an early point which would seem to sit with the finding that about 10-12% of IBM patients also have the autoimmune disease of Sjogren's and that some patients initially respond to steroids. It is thought to perhaps later become a degenerative disease which isn't assisted by steroids because they work by suppressing the immune system.

### **Prof Merrilee Needham – IBM**

Prof Needham kicked off the business of day 2 with her hallmark energy and passion. She is head of the department of Neurology at the Fiona Stanley hospital in Perth WA. She has a sub-specialist interest in IBM. We can't thank Merrilee enough - her generosity to our Association with the time and care she extends to patients and to the research of the Myositis diseases is wonderful.

Merrilee listed the key muscles involved with IBM:

- facial muscles - blinking, ability to smile
- neck flexor muscles - 60% of patients have some swallowing difficulty and up to 30% of that have severe difficulty:
- elbows
- forearm flexors
- long finger flexors
- shins
- quad weakness
- foot drop
- back

IBM is the most common muscle disease for people over the age of 40 but even then it is rare. The rate of incidence is unclear and more studies are needed. What is known is that it is rare in the Middle East and Asia.

Muscle biopsies are still the gold standard for diagnosing IBM. The biopsy will typically show:

- inflammation,
- degeneration,
- amyloid (protein)
- mitochondrial changes (battery)

If the biopsy only shows inflammation, the biopsy diagnosis is likely to be polymyositis or possibly interstitial Myositis. If the biopsy also shows degeneration, amyloid and/or mitochondrial changes, the pathological diagnosis is likely to be IBM. In about 30% of cases, one of the three cardinal features is not seen, so other factors including the clinical features, along with the antibody result need to be taken into account.

Increasingly high resolution MRI's are being used for diagnosis not instead of, but in conjunction with the clinical picture and muscle biopsy results. Ultrasound can also be used.

EMG's are useful diagnostic tools because they assist to identify if the level of weakness is due to nerve or muscle and which muscles are involved and the level of activity of the disease.

Antibody studies can also be a useful adjunct to increase the accuracy of a diagnosis of IBM. Autoantibodies against cN1A appear in 37% of IBM patients and are highly specific to IBM patients, in the right clinical context, which may lead to an understanding of the dual process of autoimmunity and muscle degeneration in IBM and also lead to a specific blood test for IBM. The same antibody is found in patients with Sjogren's and lupus diseases. Merrilee has received a grant from our Association to develop a blood test for IBM.

Sleep disorders are also common in IBM patients and sleep studies are recommended.

There are significant challenges for treating IBM.

- IBM patients typically lose 9-10% of muscles strength per year.
- there are no known drugs as yet which successfully treat IBM

- a short trial of immunosuppressive treatment is generally not recommended, but clinicians will consider it if the person is young with no contra indications to treatment, and the disease is rapidly progressive.
- supportive treatments such as exercise programs, physiotherapy, splints, diet and protein intake are recommended
- sleep assistance with CPAP
- psychological assistance -try to live mindfully and gain pleasure from small things

Hope on the horizon - 28 clinical trials involving myositis are current around the globe at present. Arimoclomal is looking like an interesting drug which helps cells to clear themselves of abnormal proteins; Rapamycin is being used in a study in France and may become a collaborative study with Merrilee, Natalizumab an MS drug which has the effect of removing inflammation is under trial.

THERE IS HOPE and Merrilee says she plans to "CRACK IT" in her lifetime.

**Question and Answer session** - a fantastic Q&A session was held with Prof Ascherman, Prof Sturgess, Prof Needham and Cathy Brand answering a wide range of questions from the audience for over an hour. It was also a pleasure to have Dr Cristina Liang in the audience.

In due course a video of the Q &A session and others sessions will be available.

### **Stephen Page - Centrelink**

Stephen has worked for the Dept of Human Services for 25 years and assists customers of Centrelink with Financial education.

Stephen highlighted the benefits available to carers:

- **carer payment** is available to people who are unable to work in substantial paid employment because they provide full time daily care to someone with severe disability or a medical condition or to someone who is frail and aged.
- **carer allowance** is a fortnightly income supplement for parents or carers providing additional daily care and attention to an adult with severe disability or a medical condition or to someone who is frail and aged. Carer allowance is not income or asset tested, is not taxable and can be paid in addition to wages, carer payment or any other income support payment.
- **carer supplement** is an annual lump sum payment to help you with the costs of caring for a person with disability or a medical condition or to someone who is frail and aged if you are receiving carer payment or carer allowance.
- **other payments are available for carers of children or students**
- **other assistance is available for continence aids and essential medical equipment**

Stephen emphasised the benefit of taking time to complete the application forms as fully as possible and ensure that all aspects of care provided to myositis patients is listed and it reflects the circumstances of the care fully. Also take the time to read the explanatory notes on the forms. The decision makers are reliant on what is spelt out in the forms and can only make their decision on the basis of this information. There's an appeal process if an application is refused with an opportunity to lodge additional evidence.

Pensioners have an obligation to keep Centrelink advised of changes in their circumstances.

Ensure an enduring Power Of Attorney is appointed well before any loss of capacity. Get a Will in place.

The Commonwealth Seniors Health card is for people who do not receive a pension but is income tested.

Also check services provided in each State eg Travel cards, Companion cards for carers

### **Robyn Ballard**

Robyn has Dermatomyositis and is also the Northern Regional Manager of OCTECT Disability Employment Services. The aim of her organisation is to help those with a disability to gain and maintain employment.

Robyn explained that those deemed not suitable to receive an aged care pension, disability pension or carers allowance may be able to receive a Centrelink benefit such as New Start or Youth Allowance but these allowances are accompanied by an obligation to be aligned with an employment services and to look for employment.

It is important to locate an employment service which will take the time to locate suitable employment for the level of disability experienced and negotiate with the prospective employer for workplace modifications and any retraining. There's government assistance to make modifications to workplaces eg bathroom modifications, scooter access, modified desks etc.

### **Dr. Julia Maclean**

Julia is a speech pathologist and Senior Post-Doctoral Fellow at St George Hospital. She has over 20 years experience working with adult patients primarily with swallowing disorders.

Julia's excellent presentation has been recorded and will be available in due course on the website and on DVD. It will be essential watching for anyone with a swallowing difficulty.

Julia described in detail the operation of 30 muscles used in the act of swallowing how she clinically assesses and treats patients.

The primary questions to ask are:

- do you have to swallow several times to clear food?
- do you take a long time to eat a meal?
- do you experience coughing or choking when eating swallowing?
- do you have difficulty with dried or hard foods?
- do you have liquid leaking out of your nose?

Swallowing difficulties can lead to aspiration which can be life threatening.

In brief, the act of swallowing, which takes only 1.5 seconds, requires the vocal chords to shut, the voice box to rise 2.5 cms, the epiglottis to go down and the food to pass. If muscles

in the throat are weakened, there isn't enough time for the muscles to carry out all the steps and choking can occur.

Julia described how a patient with swallowing difficulties is evaluated using videofluoroscopic assessments (a specialised xray of swallowing), high resolution Monometry (pressure measurements) and treated with appropriate diets to make swallowing safe.

Swallowing difficulties or dysphagia are present in 30% of IBM patients and also occur in DM and PM patients.

Julia provided tips for swallowing. It is important however to have the swallowing properly assessed to know where in the process the muscles may be weak or stiff. Generally, tucking the chin under is beneficial and swallowing in an effortful manner.

Water is difficult to swallow and it is preferable to use something more viscous such as apricot nectar or a milkshake when having a bad day.

Julia's tips for safe swallowing strategies:

- sit alert and upright
- ensure not short of breath before starting to eat
- avoid talking and eating
- chew food well
- double swallow
- remain upright after meals
- avoid problematic consistencies in food ie mixed, dry, crumbly
- single consistency easier
- have liquid wash through
- take medications with thicker consistency foods eg yoghurt, custard
- eat food with a water content eg scrambled eggs made with cream ather than a dry version

Julia's recommended compensatory techniques

- chin tucked under
- turn head if weaker on one side
- effortful swallow
- mendellsohns manouever
- supraglottic swallow

Julia also discussed installation of feeding pegs if absolutely necessary to improve nutritional intake. Pegs also have the benefit of taking the labour out of feeding but leave the patient with the despite the peg ability to eat some things for enjoyment.

Dilatation and myotomy procedures were discussed. These procedures need to be carried out very carefully by expert Ear Nose and Throat specialists.

Botox is not usually helpful in treatment of swallowing issues due to Myositis. It is only effective if the neurological input is not allowing the sphincter to relax and this is seen in other forms of dysphagia and not with myopathy.

A cookbook produced by the Motor Neurone Association was recommended.

Most importantly consult a specialist speech therapist/pathologist that specialises in neurology!

### **Dr Craig Davenport - Rehabilitation - The Challenge of Chronic Illness**

Dr Davenport is a rehabilitation specialist from the Shoalhaven region. He works as a Senior Staff Specialist of Rehabilitation medicine at Shoalhaven Memorial Hospital and David Berry hospital. He's also an honorary Senior Clinical lecturer at the University of Wollongong. He has a particular interest in the rehabilitation of Neurological and Musculoskeletal Disorders and Chronic pain. He also has qualifications in Chinese medicine and teaches Tai Chi in his spare time. Dr Davenport is well known to the Association having treated Myositis patients and addressed our group on other occasions. His presentations are always full of very pragmatic and accurate information for our audience.

Dr Davenport discussed the key tools in rehab:

- exercise therapy
- medications for symptom management
- adaptive devices
- cognitive and psychological therapies
- arranging formal and informal supports for the home

He also discussed the causes in muscle changes:

- inflammation
- reduced use
- myopathy caused by steroids

Exercise if instituted fairly early can avoid these changes taking place. Although there's still limited research it is known that resistance exercises do lead to improved strength and less affected muscles benefit more compared with the more affected muscles. It's also known that exercise is safe provided it is tailored to the individual. It's recommended to use short 15 min exercise sessions over at least 5 days per week.

Loss of aerobic capacity is caused by inefficient muscle metabolism, and weakness of respiratory function.

Mobility devices were discussed and the need to have appropriate devices for the stage of impairment.

Dr Davenport recommended that an Occupational Therapist assess the falls risk of the patient's home to advise on placement of rails, ramps, removal of obstacles etc. He also recommended consulting a dietician to discuss how to optimise nutritional intake to maintain

muscles, brain and bones - protein and calcium are very important. The presentation also included the issue of dealing with chronic pain. Persistent pain may be associated with:

- muscle tightness
- muscle trigger points
- sprains and strains
- degenerating joints
- arthritis disease
- central sensitisation

Over time, persistent pain attacks the central nervous system. Patients experience an increase in signals telling their brain that the person has pain. This can be very severe and quite real even though the point of pain isn't recording any discomfort. It's a complex issue requiring more than medical management. There is an incidence of 15-30% of people experiencing a pain level of 7+ on an ongoing basis.

The physical methods of dealing with pain include:

- postural correction
- stretching
- exercise therapy
- supportive devices
- modalities - ultrasound, heat, cold, TENS
- massage
- water-based therapy

Pain medications include:

- simple conventional - paracetamol
- moderately strong - tramadol
- very strong - Norspan patches, morphine, Endoe.Targon, Palexia
- other - Lyrica, anti-depressants,

Procedural measures include:

- injections of steroids or gels into joints, trigger points
- surgery such as spinal fusions
- implantable pain pumps

Psychological and other interventions include:

- reducing stress
- reducing depression
- improving sleep
- enjoying distractions
- mindfulness - stop, breathe, think

Complimentary medicines include:

- Mind-body therapy

- anti-inflammatory diets
- CoQ10 tablets
- Creatine
- Probiotics
- Skullcap
- Bee Propolis
- Turmeric powder
- Acupuncture
- Low level laser
- Prolotherapy

## Medical Marijuana

Currently use of marijuana straddles orthodox and alternative medicine. There are studies in Canada and Israel showing it is effective for pain. Practical experience on use of marijuana is growing and work is being done on working out the most useful doses and its impact. Very small doses have been shown to be more effective for pain control than higher doses. Legalisation is progressing in some states for certain conditions eg serious epilepsy in children.

## **Evelyn Jeleric and Gabi Nartinez - Caring for the Carers**

Evelyn and Gabi have both worked in the health, community and education sector for 25 years and are involved in the Carer programs in the Shoalhaven district. They shared their experiences and highlighted the changing landscape of funding for aged/disability care and urged everyone to become more aware of the services available, how to gain access, the costs and the need to advocate for better care.

At any time in Australia 12% of the population is in a carer role. Every carer role is unique and varied ranging from dispensing medication, providing support with finances, transport, emotional assistance, decision making, and full time personal care. The journey as a carer can be long and arduous.

Carers are at risk of:

- being socially isolated
- experiencing high rates of depression and anxiety
- experiencing low well-being
- neglecting their own health

Strategies of self help for carers:

- learn as much as possible about the illness
- understand the medications
- know what to do in an emergency
- have a support network for yourself
- let others take over
- know what's available in the community to assist the patient and carer
- look after own health
- make time for self - hobbies, do things as a couple
- take advantage of respite care

- attend to emotions
- be assertive
- plan for the future
- ensure paperwork such as Wills, Guardianship, Powers of Attorney are in place
- enjoy the good days

How to get Support? There are many avenues - some Commonwealth and other State based

- look for Government subsidised services
- for over 65yo = MyAged Care contact 1800 200 422
- under 65yo= NDIS contact 1800 800 110
- both schemes provide a bundle of funds to enable the patient to purchase assistance services
- GP provided Chronic diseases management plan enabling 5 visits
- Carers Support in each State 1800 246 636 (NSW contact) provides phone counselling, free to join
- Carers Respite and Support services - emergency respite care
- Taxi support scheme
- Half price taxi scheme
- Contact local council and ask what services are available locally - may have transport service
- Contact the State based Council for The Aging
- Welfare Rights Centre
- Community Legal Services to prepare Wills and P of A's
- ENABLE website for aids, continence issues

Advocate for better services by writing letters, contacting members of parliament.

Be aware that the new MyAgedCare and NDIS systems will result in private and public providers of services contacting patients and offering goods and services for sale. Take care to scrutinise and establish credibility before signing up. Be careful to budget costs! Report bad experiences.

## **AGM**

The meeting concluded with the AGM for the Association with Trevor Neumann being relected as President.

Current Office bearers are:

- President - Trevor Neumann
- Vice President - Christine Lowe
- Secretary - Anita Chalmers
- Treasurer - Richard Gysi
- Committee - Lachy Beckett, Dan Joyce, Kim Jones
- Public Officer - David Bunt

The annual Membership fee will rise by \$5 to \$10 from the next financial year.

Anita's secretarial role has been slightly reduced with Dan Joyce taking over the production and distribution of the newsletter.

Kim Jones will head up a fundraising sub-committee.

Myositis week in September will be abandoned in favour of Myositis month in May.

Another Conference will most likely be planned for 2019. Venue to be decided.

### **Social events**

Although each day of the conference was full of presentations, we managed to share 3 dinners together and had plenty of time to chat and network in the coffee queue and on the sunny deck at lunchtime.

At the opening dinner, we were also welcomed by a local Wollongong Tourist representative who spoke enthusiastically about the local attractions.

A video from Bob Goldberg the CEO of The Myositis Association in the USA followed. Our origins stem from the USA group when Bob contacted our Secretary Anita Chalmers in 2002 to enquire if she would like to instigate an Australian group. Bob has continued to be a great supporter of our group and attended our first conference in Adelaide 3 years ago. Unfortunately business in the US kept him from joining us in Wollongong but his video was very welcome. TMA has grown in strength and regularly has about 500 people attending their annual conference. They also hold regular online chats with medical specialists, maintain a very informative website, have a large medical advisory board and sponsor \$1/2-1M in research funds per year. Much of the current research activity has been sponsored by TMA. Videos of the latest presentations given at the TMA conference in Sept 2016 appear on their website (including one by Dana Ascherman) [www.myositis.org](http://www.myositis.org)

Finally and most importantly, the Association recognised Anita Chalmers' efforts in organising and hosting the Wollongong conference by presenting her with a gift. Anita's personal connections meant we were able to engage our outstanding speakers and liaise easily with the hotel staff. Anita thought of everything and her foresight and careful planning ensured the meeting ran smoothly and was tremendously well received. Anita's husband Geoff is such a fabulous support and always picking up the physical effort required to execute Anita's plans and he was also recognised with a gift. THANK YOU ANITA AND GEOFF.

At the final dinner, Val Dempsey regaled us with a report of her visit to the TMA conference in New Orleans in September 2016 and all that New Orleans had to offer.

All other Committee members played important roles in bringing the conference together - Trevor and Marilyn Neumann (leadership and MC), Richard Gysi (treasurer and grants), Dan Joyce (AV systems), Lachy Beckett (accommodation research and social media promotion), Roger (venue research), Christine Lowe (website, legal, grants). A great team effort!

Special thanks to all attendees and especially those who travelled from far and wide. You brought a great spirit and made it a memorable event.

A final treat - at the closing dinner we endeavoured to show a video which our Association has funded to aid the diagnosis and treatment of patients and families of a child with **Juvenile Dermatomyositis - JDM**. Technical hitches meant we could only provide a taste of the video but we have a link to share in this newsletter. We hope you'll share our pride in the production.

The launch of the video coincided with the JDM group holding their own meeting at the caravan park in Wollongong which was a great time of connection, sharing and education for their members. Congratulations JDMers!

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