# Arthritis

VICTORIA inc. OSTEOPOROSIS VICTORIA

# Annual Report 2013

## **Moving Together**

## **Our Purpose**

To improve the quality of life of people who have, or are at risk of developing musculoskeletal conditions.

## **Our Values**

- Respect and integrity
- Service and stewardship
- Excellence and knowledge
- Collaboration
- Leadership

# Strategic Directions 2013 – 2016

- 1. Creating a strong, sustainable consumer-driven organisation
- 2. Providing high quality, evidence-informed services
- 3. Developing highly respected research capability
- 4. Increasing community awareness
- 5. Influencing systemic change
- 6. Achieving recognition as a musculoskeletal health industry leader

# Contents

- 04 Who we work with
- 04 Areas of life most affected
- 05 How we help
- 06 CEO and President's Report
- 08 Our Patrons and Board
- 09 Our people
- 10 We research
- 14 We educate
- 16 We advocate
- 28 Our volunteers
- 30 Creating a sustainable future
- 32 Our financial supporters
- 33 Treasurer's Report
- 34 Statement of comprehensive income
- 35 Types of musculoskeletal conditions



- 20 We inform
- 24 We support

# **Our services**

# Who we work with?

People at all different stages of life, across the continuum of care – from prevention out in the community, to those at risk or newly diagnosed and those living with their musculoskeletal conditions for a long time.



# How we help

Arthritis and Osteoporosis Victoria has 45 years experience as the Victorian peak body for musculoskeletal health.

#### Research



#### Education

- Public awareness campaigns
- Community speakers
- Podcasts and videos
- Physical activity leader training exercise, Tai Chi for Arthritis and
- Customised training packages
- Customised training packages for consumers and health



#### Advocacv

- Consumer and health professionals surveys
- Policy submissions
- Lobbying campaigns
- **Representation on committees**
- Ambassadors
- **Clinical Leadership Group**

#### Information

- Musculoskeletal Help Line
- Website
- Fact sheets
- Service map
- Child and Family newsletter

#### **Peer Support**

- Library
- eNewsletter
- Update magazine
- Online store



#### Annual Report 2013 5

# 2013 CEO and

The Arthritis Foundation of Victoria (known as Arthritis and Osteoporosis Victoria) has been providing research, information, education, advocacy and peer support services to the community for 45 years, since 1968. We continue to work with the 1.5 million Victorians who have or are at risk of developing a musculoskeletal condition and their families and carers and with health professionals and other organisations who play a significant role in improving quality of life for the people we serve.

In order for us to continue to succeed and move together into a sustainable future, we have embarked on an exciting plan of reinvestment, reinvigoration and reorganisation to better meet today's needs of consumers, their families and carers, health professionals, service providers and the wider community.

Our Consumer and Health Professional Needs Studies were published early in 2013 and these have provided guidance for advocacy and service development. Major challenges faced by people with musculoskeletal (MSK) conditions included difficulty with tasks of daily living, managing pain and the cost of medication. The areas of life most affected included exercise, social life, work and travel. Not surprisingly, people experience the impact of MSK in different ways depending on age.

This year heralded some major advocacy work on behalf of our members, including publication of our ground-breaking report A Problem Worth Solving, which used socio economic analysis undertaken by Deloitte Access Economics to demonstrate the huge impact of MSK conditions on the community. The report revealed that, as at 2012, a staggering 6.1 million Australians lived with these conditions - 1.5 million Victorians - at a cost to the economy of \$55.1 billion. And the numbers are rising. The prevalence of MSK conditions is greater than that of any other national health priority area and unless immediate action is taken, the problem is predicted to increase by 43% over the next 20 years. Our important piece of research led to the Victorian Minister for Health, the Hon. David Davis, convening a roundtable on MSK with key MSK stakeholders, including Arthritis & Osteoporosis Victoria. In November 2013, the Minister also established an MSK Clinical Leadership Group in Victoria in which we are taking an important role. This was a great achievement for our small but effective organisation. Given we represent the interests of such a large number of people living with over 150 different types of MSK conditions, we are uniquely positioned to influence lasting change in the sector. Now the problem is being recognised, a representative group of industry leaders in Victoria will help the government set priorities for reform in the way services are delivered and resourced. Professor Peter Choong. who was honoured with our Lorin Prentice Memorial Award in 2012, was named Chair of the MSK Clinical Leadership Group.

Our wonderful Peer Support Groups and volunteers worked tirelessly and with great devotion and spirit to continue to support a broad range of services. Some of Arthritis and Osteoporosis Victoria's long term "treasures" were recognised in prestigious awards and influential advocacy positions. Beryl Logie was awarded the Council of the Ageing Victoria's Senior



## **President's Report**

Achiever Award and Noel Smith was appointed to the Chair of the Public Transport Access Committee and a member of the Austin Health Consumer Advisory Committee. In 2013, Noel Smith finished his term as a Board Director and was appointed as Arthritis and Osteoporosis Victoria's Senior Consumer Ambassador.

Our capacity to reach more people is enhanced by the quality of our programs and information. As this Annual Report details, we commenced a series of very popular webinars and continued to run other development programs and seminars for health professionals and peer leaders. Our website was the State not-for-profit winner of the 2013 Australian Web Industry Association Awards and we are broadening our messages to more people via popular social media platforms and a regular eNewsletter Around The Joint. Demand for our MSK Help Line and participation in many of our consumer programs increased significantly in 2013.

In the past twelve months we continued to develop strong research partnerships and to undertake and support unique research with significant relevance to consumers. This included projects on pregnancy, post natal care and parenting with rheumatoid arthritis; mapping the needs and use of medicines and pain in the workplace and a literature review on warm water exercise.

We will continue to work together with consumers, health professionals, government and other organisations to reduce the massive prevalence of MSK conditions, increase community awareness and improve the quality of life of people with MSK conditions. To do this we need the ongoing support of our members and donors and increased commitment from government and corporate Victoria. Our strategy to build relationships in 2013 showed signs of increasing financial commitment from government, with an increase in revenue from 3.4% in 2012 to 11% in 2013. It is pleasing that we received over a quarter of a million dollars in project funding from the State Government this year, but disappointingly only \$32,000 of that was recurrent funding. This is not nearly enough to support the 1.5 million Victorians living with MSK conditions.

Consistent with many other not-for-profit organisations, our traditional sources of income did not perform as well as expected in 2013 but, due to responsible financial management, we saw a significant increase in return from equities. Placing our shareholdings in licensed investment companies and banks provided an additional income stream and capital growth. We also received much appreciated grants from ten philanthropic trusts and foundations in support of the good work we do.

The four new Directors of the Board, who joined us in 2013, brought a wealth of experience and expertise in areas such as finance, corporate development, government and marketing. The strong interest in Board positions contributes to our capacity to continue to provide responsible governance.

Arthritis and Osteoporosis Victoria's recognition as a leader in promoting the importance and impact of MSK health increased substantially in 2013. Our strong sector leadership continues to be driven by the needs of consumers and a commitment to MSK sector change. By continuing to build strong relationships, we are 'moving together' to improve MSK health and wellbeing for all Victorians.

Linda Martin, Chief Executive Officer Judge Philip Misso, President

# **Our Patrons and Board**

#### **Patrons-in-Chief**

Hon Alex Chernov AC QC Governor of Victoria

#### Patron

Professor Sir Gustav Nossal AC CBE FAA FRS

#### **Honorary Life Governors**

His Honour Barry Dove QC Ms Heather Rose Mr Noel Smith Dr Leslie Koadlow AM Mrs Alice Petty

#### **Chief Executive Officer**

Ms Linda Martin BA, Dip Ed. BSW, MSW

# **Directors of the Board**



**President** Judge Phillip Misso *BJuris, LL.B* 



**Treasurer** Mr Jim Dixon FCPA, MBA, B Comm, B Ed



Vice President Mr Stephen Fitzpatrick Dip Bus (Accounting), AHSFMA, ACHSM, IPAA



Professor Peter Brooks AM, MD FRACP, FAFRM, FAFPHM, FRCP (Glas, Edin), MD Hon Causa (Lund)



Ms Janine Fisher *GAICD* 



Dr Ian Relf MBBS, BSc(Hons), MSc, Dip RACOG, FRACGP, FAMAC



Mr James Coyle BEc, MSc, CIMA, MAICD



Mr Geoffrey McDonald Bowll GAICD, Fellow of AMI, Member ASMI



Mr Duncan Langdon FCPA, MBA, ACIS, ACSA, MAICD



Mr Anthony Raitman BBus/BArts



Ms Bernadette Dennis



Mr Noel Smith Retired as Board Director April 2013 Appointed an Honorary Life Governor



Ms Naomi Creek Resigned as Board Director January 2013

## **Our people**

We draw on the skills and knowledge of a dedicated Board of Directors, enthusiastic and committed staff, passionate volunteers and interested and informed consumers, all working to achieve our purpose of the best possible musculoskeletal health and wellbeing for all Victorians.





### Talk to a nurse

If consumers and health professionals have a question about pain, medication, MSK conditions and where to access the best support and services, they can talk to an Arthritis and Osteoporosis Victoria nurse on toll free: 1800 263 265.



# Our volunteers and peer support leaders

Arthritis and Osteoporosis Victoria highly values the 250 volunteers who contributed to our work in 2013. People volunteered in a range of roles including warm water exercise leaders, community speakers, the Telephone Information Service, working in the Opportunity Shop, helping out at fundraising events, public awareness campaigns and providing general administration support to staff.

**Beryl Logie** an Arthritis and Osteoporosis Peer Support Leader and Community Speaker was awarded the Council on the Ageing Victoria Senior Achiever Award on Thursday 3 October 2013 for her work as the President of the Melbourne Osteoporosis Peer Support Group for 16 years. As one of only 14 successful candidates, Beryl was selected for her outstanding contribution in helping people who live with the pain and discomfort of osteoporosis and for her advocacy to the broader community.

People fortunate enough to come in contact with Beryl describe her as an inspiring role model who encourages and motivates them to live positively with their condition. She has helped many people live a healthy and fulfilling life.



# We Research

Currently there is no cure for most musculoskeletal conditions, however we know that research has made a great difference to the quality of life of people with some MSK conditions. That is why it is important that Arthritis and Osteoporosis continue to invest in more life changing research.

As part of our committed approach to finding the best information and support for people in this state, Arthritis and Osteoporosis Victoria is developing a highly respected research capability to keep you up to date on things that are making an impact.

In 2013, we continued to develop important research partnerships with leading universities, researchers and clinicians. We also identified the need for a research knowledge exchange and after preparing a strategy, the document was sent to researchers and clinicians across Victoria for comment. The draft Arthritis and Osteoporosis Victoria Research Strategy 2014-2019 is consumer-outcome focused with clear priority for translational research. In 2014, we will undertake a consultation with consumers before finalising the Strategy and implementing it.

In an effort to support knowledge exchange, plain language summaries of all our completed research projects are available from our website.

## **Our research** partners

In 2013, we applied for new research funding with:

- University of Melbourne and Department of Orthopaedic Surgery at St Vincent's Hospital
- La Trobe University
- University of Ottowa, Canada





Fast Facts: \$55.1 billion MSK problem

F INIC

10 Arthritis and Osteoporosis Victoria

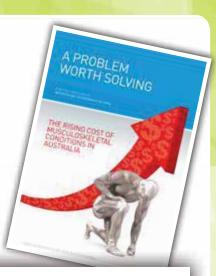
December 2013

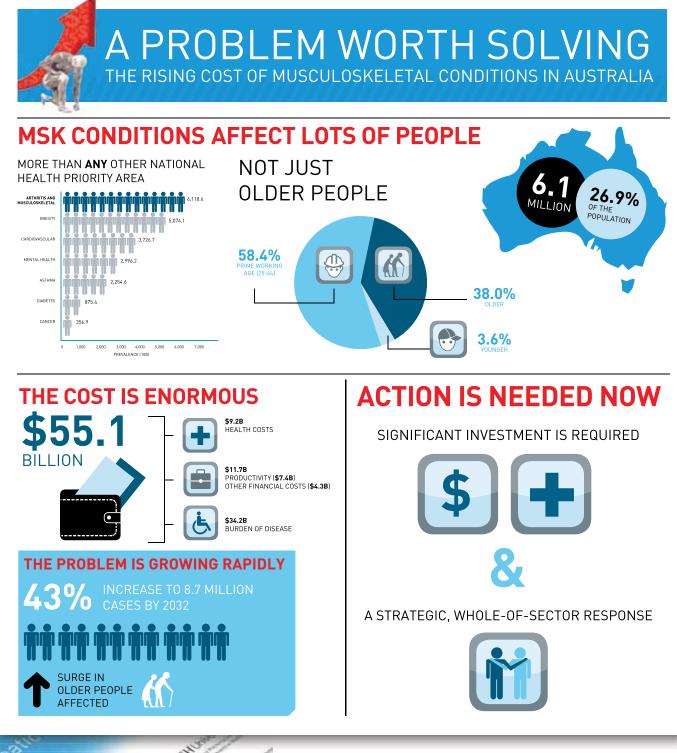
Victor

Consum

## **A Problem Worth Solving**

In 2013, we published our landmark socioeconomic report *A Problem Worth Solving: The Rising Cost of Musculoskeletal Conditions in Australia.* An independent analysis of results through Deloitte Access Economics, found that as at 2012 MSK conditions cost the Australian economy \$55.1 billion in direct health costs, lost productivity, other financial costs and reduced quality of life. The report also projected a 43% rise in MSK cases over the next two decades to 2032.





500

# We Research





### Warm water exercise program making a difference

For the past 30 years, our warm water exercise program has received some great anecdotal feedback on the benefits to people with arthritis and other musculoskeletal conditions.

In 2013, we formed a partnership with Monash University to conduct both a systematic review of high quality published literature about the benefits of warm water exercise and gain some hard evidence through an observational study of our classes.

The results of the expert review of literature, led by Dr Anna Barker of Monash University, found that warm water exercise provides many benefits for people with musculoskeletal conditions. Importantly, there were no reports of any harmful effects of warm water exercise. Those participating in warm water exercise experienced a moderate reduction in pain, and a moderate improvement in physical function and quality of life.

The findings were used to develop six workshops run by volunteer leaders on the benefits of warm water exercise and the most effective exercises. The observational study of our program continued throughout 2013 exploring whether particular exercises decreased pain levels, improved function, decreased feelings of stiffness and improved quality of life. The results of the study will be analysed and reported in 2014.

## **MSK trials in Australia**

Monash University, the Cabrini Institute and Arthritis and Osteoporosis Victoria formed a partnership in 2013 to explore the scope, funding and publication of musculoskeletal trials in Australia. The project led by Professor Rachelle Buchbinder reported that Australia, in spite of relatively low funding in MSK research, has generated some quality research findings. The project also highlighted the need for more research to be done on how evidence is implemented into health practices. A report will be published in February 2014.

> Fast Facts: 1,295 people at community talks



## Mapping the needs and use of medicines

We are supporting a PhD candidate, Dianne Lowe from LaTrobe University, in her study to identify the needs and preferences of people with arthritis and other chronic conditions when managing their medicines, and the impact of common problems they face. The project *Multi-morbidity medicines journey: mapping the problems and needs of people with 'arthritis' for using and managing medicines'* will be completed in 2015.

## Pain in the workplace

A research grant has enabled us to partner with Latrobe University to explore the barriers for people with persistent pain to maintain productive employment. The study in 2014 will be led by Dr Jodi Oakman, to look at both the barriers and enablers for Australian workers who have persistent musculoskeletal pain in maintaining their jobs and careers.

### Pregnancy, post natal care and parenting with rheumatoid arthritis

In 2013, we began a project with the University of Melbourne to better understand the type of information needed and the best way to deliver it, for women with rheumatoid arthritis in pregnancy and early parenting. The project, led by Dr Ilana Ackerman (University of Melbourne) and Associate Professor Andrew Briggs (A&OV) will be completed in 2014 and was supported by the Angior Family Foundation.

# Expanding Australia's first lupus registry

In 2013, we committed to support the establishment and expansion of the Australian Lupus Registry for a further five years. This important initiative, led by Professor Eric Morand from Monash University, will build a databank of information gathered from people with lupus to increase research capacity and ultimately improve treatment outcomes.

# We Educate



Each year the number of people taking part in our training programs and courses is increasing. In 2013 there was a 41% increase in the number of health professionals and service providers attending our professional development programs. This is a positive trend that supports our goal to focus on building the capacity of people and services to meet the needs of people living with arthritis and other MSK conditions.

Arthritis and Osteoporosis Victoria's new standardised feedback also showed that 98% of people who took part in training programs felt the information was relevant and met their needs - 97% said they were confident to apply their learning and 99% thought the trainers were effective.

Highlights of the year included:

- 73 new leaders trained in Nordic Walking, Tai Chi for Arthritis and Tai Chi for Osteoporosis
- 103 warm water exercise program leaders attended additional training
- 50 people attended the Nordic Walking presentation to Heart Foundation walking group in Albert Park
- 24 Better Health Self Management leaders updated their training
- Training sessions were held in metropolitan Melbourne and regional areas including Benalla, Bendigo, Ballarat, Cranbourne, Warragul, Morwell and Sale

## Training partnerships and programs

We provide training programs on a consultancy basis across the State, with courses and programs tailored to meet specific needs. In 2013, they included:

 'MSK@Home' Home and Community Care (HACC) assessor training, with the Victorian Department of Health



- Training and information sessions delivered to medical and allied health students via the Macedon Ranges and North-West Melbourne Medicare Local
- Seminar on inflammatory arthritis run in partnership with the Victorian Branch of Exercise and Sports Science Australia
- Training and information sessions on rheumatoid arthritis for the Victorian Medical Professionals Foundation
- Training for BUPA health coaches, National Pharmacy assistants and Benetas staff.



## Warm water exercise leader training program

With the assistance of a grant from the Lord Mayor's Charitable Foundation, Arthritis and Osteoporosis Victoria produced an audio-visual training resource for warm water exercise leaders. The resource provides guidance and additional ideas for leaders in the areas of class leadership, different forms of exercise and enjoyable class activities. The training resource is a valuable resource for our 'Waves' and Peer Support Group warm water exercise leaders and will be available to other warm water exercise leaders in the community.

## **Webinars**

Webinars for health professionals have continued to attract a strong audience and are in high demand.

In 2013, our webinars 'Understanding Fibromyalgia' and 'Low Back Pain – Less is More' attracted hundreds of viewers. This positive response has led to the development of a series of six webinars on musculoskeletal health which will be conducted in 2014.

This series will involve targeted partnerships with health professional associations and organisations to promote and extend its reach.

### Bilingual Health Educator Project

Arthritis and Osteoporosis Victoria received a grant from Brimbank Municipal Council to partner with the Multicultural Centre for Women's Health (MCWH) to deliver education sessions in Greek, Italian and Vietnamese to community groups.

In 2013, nine sessions were delivered to 345 participants. In addition to this, there were four Nordic Walking 'come and try' sessions and information stands at the Croatian Community Day Expo, the Ageing In Australia Cultural Diversity Expo and the Knox Hungarian Seniors Health Information Day.

# We Advocate

Arthritis and Osteoporosis Victoria is committed to uncovering the challenges that our consumers and health professionals face.

In 2013, we established the foundation for advocacy on behalf of consumers and health professionals that resulted in:

- The October launch of A Problem Worth Solving by the Victorian Minister for Health, the Hon David Davis MLC which attracted significant national media coverage
- Lobbying the Victorian Government about the need to address musculoskeletal conditions
- Convening a musculoskeletal roundtable with Minister Davis and major MSK stakeholders
- The establishment of a Victorian Musculoskeletal Clinical Leadership Group



#### Musculoskeletal Clinical Leadership Group (MSK CLG)

Arthritis and Osteoporosis Victoria has taken a leadership role after advocating to the Victorian Government to facilitate a MSK Clinical Leadership Group. The MSK Clinical Leadership Group was formed late in 2013 to take a coordinated state-wide approach to guide and inform policy, education and program development and to improve the care of people with musculoskeletal conditions.

It will undertake big picture strategic planning and provide advice to the Department of Health and the Minister. The purpose of the MSK Clinical Leadership Group is to influence clinical and service behaviour, encourage good practice and innovation and facilitate improved care pathways for people with MSK.

It is Chaired by Professor Peter Choong, winner of Arthritis and Osteoporosis Victoria's 2012 Lorin Prentice Award.

### **Ambassador initiative**

Arthritis and Osteoporosis Victoria encourages the leadership of consumers that we represent.

In 2013, retiring Board Director Noel Smith was awarded the honour of Life Governor in recognition of his work in the health system over 60 years. He was appointed Senior Ambassador, leading the advocacy work of our Consumer Ambassador Initiative.

Noel was diagnosed with juvenile arthritis at the age of 16 but it wasn't until he had cardiac surgery and later rheumatoid arthritis, that he was given an opportunity to rehabilitate and self-manage his health, medication and lifestyle choices.

His voluntary work with Arthritis and Osteoporosis Victoria began with training as an Arthritis Self Help Course Leader, and later he went on to serve as a Board Director and Vice President. He is also a strong voice for people with musculoskeletal conditions as a member of the Public Transport Access Committee, Austin Health Consumer Advisory Committee and is the consumer representative on the MSK Clinical Leadership Group.

Through the support of Arthritis and Osteoporosis Victoria and the Victorian Department of Transport, he presented papers in Japan in 2004 and Hong Kong in 2010 and more recently at the 17th Annual Chronic Diseases Network Conference in 2013.

# We Advocate

In 2013, we published the results of three surveys that have provided evidence-based data for us to advocate for policy reform, research, services and public awareness campaigns.

#### **Consumer Needs Survey**

Victorians identified a greater need for advocacy and services by listing the top ten areas where they faced challenges:

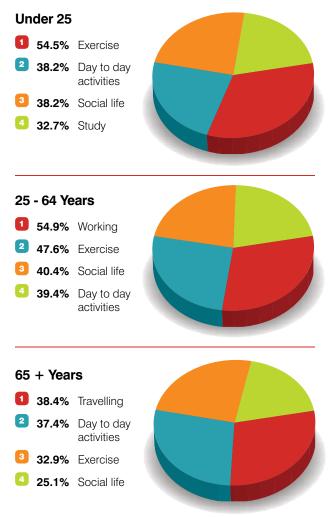
- Difficulty doing day to day activities 47.8%
- Managing pain effectively 45.0%
- Cost of medication 38.6%
- Design of everyday products, e.g. medication packages, jars 33.9%
- Waiting times for specialists 29.3%
- Managing multiple conditions 28.8%
- Public understanding of the impact of musculoskeletal conditions 24.3%
- Difficulty paying costs of managing condition (medications, specialist fees) 23.9%
- Access to services pools, support groups, exercise classes 17.9%
- Design of public spaces public toilets, footpaths, bus stops 15.2%



# Areas of life most affected

Musculoskeletal conditions often cause physical problems like swelling, stiffness and pain. We wanted to explore more deeply how musculoskeletal conditions impact different areas of life and how that changes at different ages. The top four issues from our 2012 Consumer Needs Survey are:

### Top four issues:



## Health professionals survey

Health professionals often face many barriers to treating people with arthritis, osteoporosis and MSK conditions. A survey of more than 220 rheumatologists, general practitioners, nurses and allied health professionals in urban and rural areas highlighted that there is more to be done in providing information and access to services.

The online survey gave professionals the opportunity to identify the top issues they face in managing patients including:

- Difficulty finding appropriate facilities (e.g. warm water pools, community halls etc.)
- Cost/access to aids and equipment for patients
- Lack of services for mild to moderately affected people
- Too many patients/waiting lists/not enough time to spend with each patient
- Health literacy of patients
- Costs of medications and services to patients
- Lack of awareness of my professional role in treatment (by patients and other health professionals)
- Not enough written resources for patients (about pregnancy, medications, co-morbidities etc.)
- Patient understanding of the role of complementary therapies

Other professional challenges included long surgical waiting times; lack of communication between health professionals; not enough resources for patients in rural areas and Medicare subsidies being too low.

#### Lupus survey

Lupus is a condition that is often hard to diagnose and because people often look well, this can impact on how others understand the disease.

We discovered this and other impacts through a project which followed people, their carers and health professionals through their journey with lupus! Exploring the needs of Arthritis and Osteoporosis Victoria's stakkholders: The journey with Systems December 2013

We gathered information in a number of ways via focus groups, consumer surveys, interviews with health professionals treating patients with lupus and a review of literature.

Individuals with lupus shared common symptoms that affected their quality of life including fatigue, pain, depression, emotional difficulties, sleep disturbances and cognitive dysfunction. Other issues were body image, sexual function, inability to plan ahead because the impact of the disease is unpredictable, reduced career prospects and lack of understanding or discrimination by their work mates and supervisors.

The top 10 concerns identified in the survey further reflect these findings as well as concerns about access to services:

- Cost of medication (63%)
- Managing pain effectively (60%)
- Difficulty doing day to day activities (57%)
- Managing multiple conditions (55%)
- Difficulty paying to manage the condition medications, specialists' fees (46%)
- Public understanding of the impact of musculoskeletal conditions (45%)
- Waiting times for specialists (41%)
- Design of everyday products e.g. medication packages, jars (31%)
- Getting appropriate insurance (health, travel, life etc.) 28%
- Waiting times for GPs (25%)

# We Inform



Our 2012 Consumer and Health Professional Needs surveys cemented how important it is for Arthritis and Osteoporosis Victoria to raise awareness about musculoskeletal conditions.

In 2013, we responded to that role – delivering a large range of information services for individuals with musculoskeletal conditions, their carers and families as well as health professionals and the wider Victorian community.

#### **Community Speakers** spread the news

Community Speakers are trained volunteers who provide an invaluable opportunity for groups to interact and learn more about musculoskeletal conditions and the work of Arthritis and Osteoporosis Victoria.

In 2013, our Community Speakers delivered 51 talks to 1,295 people. At 14 of those talks we used an interpreter for those people from culturally and linguistically diverse backgrounds. We trained 17 new Community Speakers.

> Fast Facts: 281,696 Website Visits



### Website

#### www.arthritisvic.org.au

In 2013, we undertook major upgrades to our website which had 281,696 visits and 697,455 page views. This is a significant increase from 164,278 visits and 406,685 page views in the previous year.

The website was named state winner in the 'Not-For-Profit' website category at the 2013 Australian Web Industry Association's Awards. Our website was created to Level A and AA accessibility standards of the Web Content Accessibility Guidelines (WCAG) 2.0. By conforming with these guidelines our website is much more user-friendly.

### **Visit our library**

By becoming a member of Arthritis and Osteoporosis Victoria you gain access to our comprehensive library. We have books, CDs, DVDs, magazines and publications. We are constantly adding new resources. You can search the collection online at www.arthritisvic.org.au or visit us at 263 – 265 Kooyong Road Elsternwick.

### Our Musculoskeletal Help Line

#### 1800 263 265

Arthritis and Osteoporosis Victoria's free Help Line is staffed by trained nurses and provides an invaluable service to the community that gives people diagnosed with a musculoskeletal condition, their families as well as health professionals:

- Access to current information
- Help to manage a condition
- Assistance in navigating the health system

In 2013, our qualified nurses answered 825 calls from consumers and health professionals seeking information.

- 25% of all enquiries are by email
- 18% from men
- 35% between ages of 41-65 years
- 4% calls come from interstate
- 13% are from carers

Next year the data collection system is being enhanced to prepare the service for a review.

"I have been a nurse and midwife for 30 years. I think of my work on the Help Line as problem solving. I try to help people navigate through the health system and tap into the right networks." – Margaret Ricardo

# We Inform

## **Arthritis Map**

The Arthritis Map is a valuable online resource that assists people living in Victoria prevent or manage chronic musculoskeletal conditions by helping them to locate the programs and services they need.

The map helps address the increasing impact of arthritis and other musculoskeletal conditions in communities across the state of Victoria. It is used daily by our nurses on the Musculoskeletal Help Line and volunteers on the Telephone Information Service.

Arthritis and other musculoskeletal conditions have reached epidemic proportions, affecting almost one-third of the population, with these numbers steadily increasing. Access to appropriate programs and services to both manage and prevent these conditions is vital.

### **Update and e-newsletters**

Regularly keeping health professionals and people with arthritis and other musculoskeletal conditions informed of the latest news, events, and research is of great importance to Arthritis and Osteoporosis Victoria.

We publish four editions of *Update Magazine* each year and distribute to 5,000 members and health professionals.

Our e-newsletter Around the Joint is published seven times a year and distributed to 7000 people.

In 2013, other more specialised regular publications include the Youth and Family Services Newsletter (twice a year), Consumer Information Bulletin (four times a year), Waves Leaders e-newsletter (six times a year) and Connect (an annual newsletter for raffle ticket sellers).



us on g tivities to

Arthritis

ving with gout

alt

Staying in the game



v research report released by Arthres and pontes Victoria projecto a starting surge in outer Auto war mutocassedena (MSN) concepts over of two releases

Lanching A Postern Woom Solving: The road cost of manoulosteness costs on Automation, Arbitro and Osterporoso vectors CEO Linds Martin revealed that news are the Automation of cases will be the automation reads by 2012 - a 43% scenario

Based on excert analysis provided by Delotte Access Economics, A Probain Hours Solving reports the cost MSX to the Asstration economy at \$55.1 billion of

The Grant nearin oces component accounts a Stady Sty 2 ballon, including analy the possible and and statements are as

ale

Spring

Arthritis

tait in the report pairing

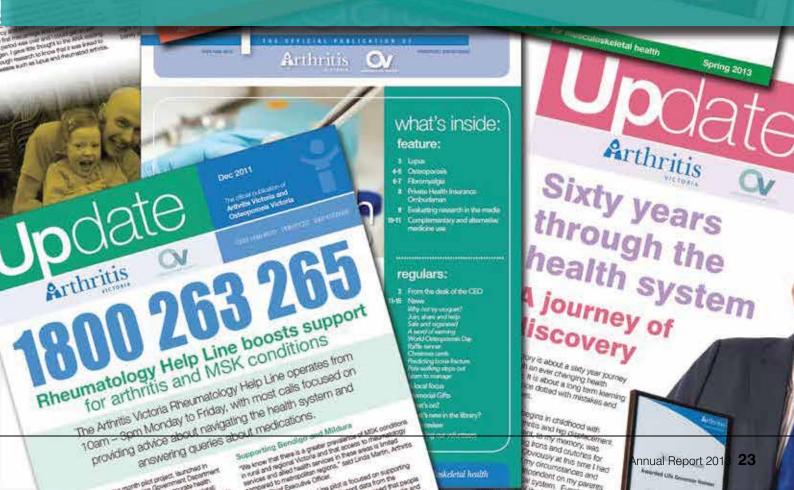
Detail in the report paints on allomming persons is likely to happen next. The heads cost and to costoouthing alone, and more common form of a likely to state the state of the state of the head is a 2004, to state of the state of the state bases is 2012. A Policie billion is 2004 and how been is 2012. A Policie billion is 2004 the next base de-

Update magazine has given me information I couldn't find elsewhere. I enjoy reader's stories as I can relate to them and don't feel so alone.

Arthritis

Aini

Ar ict



# We Support



Connecting with other people with arthritis, osteoporosis and musculoskeletal conditions is a valuable way to share experiences, gain support and insight.

Arthritis and Osteoporosis Victoria had 61 Peer Support Groups in 2013, with more than 2,200 members around the state. Peer Support Groups offer a range of activities from informal gatherings to more formal events with guest speakers and exercise classes.

There are enormous benefits taking part in a Peer Support Groups. It reduces isolation and increases social activity with people who have had similar experiences. Peer Support Groups also provide information, reassurance and can boost confidence so that individuals manage their condition and more effectively communicate with doctors and other allied health professionals. Belonging to a Peer Support Group can provide the opportunity to:

- learn from each other
- realise you're not alone
- gain support by sharing experiences and feelings with others in a similar situation
- talk about fears and concerns
- gather and share information and resources
- · learn practical ideas to better manage conditions
- learn about community and health services and how to use them

Many groups have volunteers who lead warm water exercise, chair based exercise, Nordic Walking and Tai Chi for Arthritis classes. Members have the opportunity to participate in these exercise classes with friends, close to home, on a weekly basis.

#### Telephone Information Service 1800 011 041

The free Telephone Information Service is run by volunteers and offers information and a unique peer-to-peer support structure. In 2013, 19 volunteers answered 968 calls from people wanting to talk about their condition or receive educational materials.

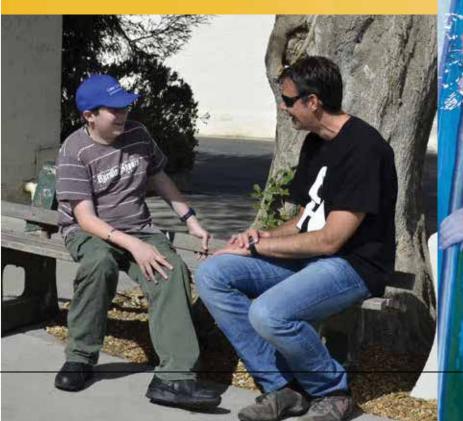


Within our support group

 I have found many caring
 members who have
 similar problems. Being
 able to talk with them
 has helped make a great
 difference to my way of
 thinking and hence my
 lifestyle.

Jane Mulloy, JAM Support Group Inc.,

Wodonga



# We Support



### **Youth and Family Support**

Family gatherings and camps are a chance for parents and children with Juvenile Idiopathic Arthritis to get together, have fun, and make new friends.





### **Camp Limber Up**

In 2013, Camp Limber Up was held at Portsea Camp and had 82 participants. From Friday night to Sunday afternoon, children, their siblings and their parents were encouraged to learn and try new things in a fun environment.

Camp Limber Up offered outdoor activities including the breath taking giant swing and flying fox, which children of all ages took to with gusto. In the water, the kids all suited up for snorkelling and canoeing, and even enticed a couple of the parents to take part.

Camp Limber Up also provided an opportunity to ask curly questions about medication, new treatments and the impact of juvenile arthritis in a non clinical setting. Dr Angela Cox paediatric rheumatologist and Anne Augustine, paediatric nurse educator from Monash Children's Hospital ran the information sessions.

A highlight of the 2013 camp was a visit by children's author Nicky Johnston. She also ran an arts and crafts session so she could talk to the kids and gain a better understanding of their experiences.

In 2014, Camp Limber Up will be held in October at Marysville.



## Warm water exercise program

Arthritis and Osteoporosis Victoria's warm water exercise program continued to provide great service on a weekly basis throughout 2013 to over 1000 people with arthritis and other musculoskeletal conditions. With 45 classes a week at 19 different pool venues around metropolitan Melbourne, the program is supported by a dedicated group of over 100 trained volunteer leaders. The reach of the program is supplemented by the exercise groups conducted by Arthritis and Osteoporosis Victoria's Peer Support Groups. The provision of group exercise is not only vital for the physical health and well-being of people with arthritis and other musculoskeletal conditions, but also for the social connection provided by such activities.

Social life affected, not stopped.

#### Annual Consumer Conference

In March 2013, the annual consumer conference was held at St Kilda Town Hall and had the theme 'When The Mind Matters'. Hosted by TV personality George Donikian, the event was attended by 159 people who heard guest speakers Professor Eric Morand of the Monash Institute of Medical Research, Dr Craig Hassed and Dr Louise Schaper explore the science behind mindfulness, medical decision-making and the mysteries of e-health.



# **Our Volunteers**



# Volunteers are priceless! >>

Our volunteers are skilled people who dedicate an enormous amount of time to enable us to expand and enhance our service delivery.



#### **Community Speakers**

Daisy Antoniou Elaine Bee Melissa Coulson Nicole Evered Olga Givoye Rosalie Grenville Alfred Law Beryl Logie Elizabeth McCrea Annie McPherson Bill O'Connor Margaret O'Doherty Alison Owen Noel Smith Jeanette Tabone Kay Timmins **Elizabeth Voss** Helen Wakeling Lee White

#### **Office Volunteers**

David Chen Naomi Heeney Sabina Barylah Gerry Black Garth Richards Tomer Shachar Nancy Yeomans Bill Hunter Ian Pass Vicky Genius Rosie Freeman Shaynie Ashkenazi Popi Sardelis Richard Ward Romina Atai

#### **Opportunity Shop**

Annette Barwick Elizabeth Becker Anne Brown James Brown Shirley Browne Helen Carter Yvette Cavzer Clementina Davies Maureen Devlin Kath Dight **Claire Geddes** Noreen Hassett **Betty Hastings** Ailsa Jaques Renate Kupfer Judith Leerson Wendy Loveridge Joan Mason Wendy McKaskill Doreen McKenzie Gordon Meyers Maureen Meyers Gwen Moxey Ruth Nette Monica Nielsen Jan Nielsen Jane Parsons Barbara Prouse Maureen Reid Vicki Shackleford Helen Thomas Maria Tolley Kate Wood John Young Graham Scott



#### Telephone Information Service 1800 011 041

Monica Abrahams Joan Bray Eve Caplan Joan Cotton Susan Donaldson Bruce Harvey Lynette Hinton Lesley Hunter Sandra Jolly Barbara Lock Jonathan Maltz Barbara Mowat Elizabeth Peck Judy Pullar Anna Sorensen Allan Stewart Robyn Taylor Helen Wakeling Nancy Yeomans

#### Waves - Warm Water Exercise

Sharon Connor Catherine Anne Langlands Vivien Marks Belinda Pinskier Anna Scott Michelle Axiak Michele Goodrich Dora Mouzakis Leon Creighton Jennifer Smallridge Ian Aldridge Catherine Calder **Reginald Hargreaves** Jenny Smith Azmina liap Janine Gale Robyn Park Cimen Rasih Dorothy Singe Janice Dawson Dorothy Gawthorne Jill Anjou Judy Bailey Carole Barber Gail Bevan Sue Brown Margaret Moyle Vera Fedorovskava Peter James Joan McPhee Deanna Twomey Cathy Revell Lyn Scholes Robyn Brown Lynette Diss Teresa Goldsbrough Judith MacPherson Jan McMenamin Vicki Morzinek **Rosemary Padgett** Jo'Ann Carell Pam Fitzgerald Pat McKinnon Jim McKinnon Barbara Reid Renee Wood Jean Donaldson **Denise Parrott** 

Freda Schelling

Pat (Elizabeth) Stark Mary Stuart-Jones Judy Wexler Julie Woodward Beryl Hennessy Mary Maguire Miriam Hicks Vaal O'Keeffe Lee Knight **Caroline Brooks** Marion Cummins **Beverlev Ednie** Nicole Evered Margot Lyons Jill Lowe Anne Te Teira Kylie Van Dinteren Ming Guo Margaret Mitchell Ann Williams Roy Workman Jayant Bapat Yvonne Brown Lois Miles Julie Madjarevic Angela Khan Tina Lam Janet Farnsworth Rosalie Grenville **Colleen Hanbury** Helen McIlrov Bill O'Connor Nellie Plunkett Allan Stewart Patrick Byrne Margot Anders Judith Steele Heather Feldman Angela Maisano

Gary Milburn Pauline O'Brien Patrick Woodlock Liz Robinson Bart Biviano Joan Bray Margaret Hallam **Bill Karambatsos** Marion Linke Janie Nichterlein Noel Smith Lesley Smith Robyn Bate Salai Cin Monika Friedrich Lorraine Hancock John Hird Irene Kayler-Thomson Kay Maley Julie Minniti Ken Missen Evelyn Missen Fave Noble Alison Richards Michelle Sutherland Lisa Williams John Albanus Beryl Baker Janice Shnider Lena Rodger Lillian Hayes Fran Feldman John Poletti Gillian Poulier Jenny Rutherford Gwen Adams Shelagh Mason-Jones Edna McGregor Robyn Talbot

Carmel Arenivar Maria Tarascio Susan Allan Wendy Cohen Olivia Lie Stanley Hanbury Kee Lee-Burman Rhonda Killingsworth Carmen Ludeman Jeanne Thorburn Carlina Ridgeway

#### Youth and Family Services

Alice Baker Catherine Congerton Monique Crinall Fiona Naughtin Stuart Woollett

# Creating a Sustainable Future

At Arthritis and Osteoporosis Victoria, we have ambitious plans to reach even more people with a musculoskeletal condition, develop new programs and find new ways to help them live healthier and happier lives. As part of 'Moving Together', our scope and target audiences are broader now and will continue to grow into the future.

In 2013, we delivered the second year of a three-year plan to reinvigorate the organisation for a more sustainable future. Part of that was implementing new systems and processes. We are proud of the rich history of Arthritis and Osteoporosis Victoria and we recognise the need to expand our influence and resource base to ensure continued success into the future.

Despite musculoskeletal conditions being a National Health Priority Area since 2002, affecting more people than any other area, funding for musculoskeletal conditions from the Commonwealth and State Governments is small.

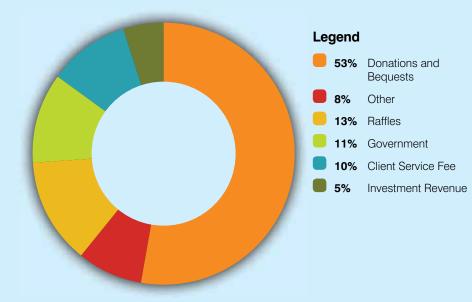
Largely, we rely on the generosity of individuals who support us financially by:

- Giving to our direct mail appeals
- Joining our regular giving program, Fired Up
- Being a member
- Giving to our community collectors who door knock for donations
- Buying our raffle tickets
- Shopping at our online store
- Holding a fundraising event or joining an event such as our team for Run Melbourne
- Leaving a gift in a Will

The support that we receive from the community is a clear sign that they value the work that we do and the help that we provide.

Fast Facts: Representing 1.5 million Victorians

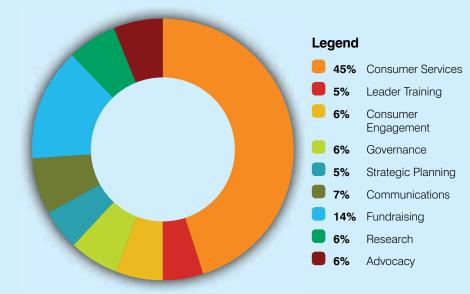
#### **Income by Source**



## Leave a bequest and a lasting legacy

To find out more, contact our bequest team on 1800 011 041 or email us at afv@arthritisvic.org.au

#### **Expenditure by function**





# Our Financial Supporters

We very much appreciate and would like to thank all of our financial supporters, both big and small. Here are some that we think are extra special:

#### **Estates**

Lindsay James Baldy Marion Poppwell Joe White Harry Francis Malkin Betsy Floyd Barbara Shearer Helen Delamain Glascodine Patricia McArthur Edwin Parker Rose Dalmody Dinah McPhee Margaret Murray Stephanie Price

#### Individuals

Sam Abrahams **Rita Andre** Nicholas Atkins **Dorothy Bailey** Nick Baker Geoffrey Baker John & Jennifer Barke John Brownbill Jeff Campbell Loraine Chessells John & Chris Collingwood Ainslie Cummins Tony Cust George Dore OAM John Ellson Neilma Gantner

George Gilbertson Catherine Gray Jo Grigg Shane B Hammill Alan Jones Mirko Klokocki SM Linsdell Lady Gwendolen Lloyd **Gloria Ann Meadows Beverley Miller** Norma Minney Lynton Morgan Harold Mower Mary O'Sullevan Judy Reid **Dulcie Richards Rosemary Richardson JS** Rogers MS Ross AM Greg Shalit & Miriam Faine June Smith **Robert & Beverly Squire** Graeme Thomson John Toomev Elizabeth Turnbull Ralph & Barbara Ward-Ambler Lee White Edel Wignell Tony Zhang

### Philanthropic trusts and foundations

The Lorenzo and Pamela Galli Charitable Trust The Russell Foundation The Landman Foundation William Angliss Charitable Foundation Bruce McDonald Trust Australian Communities Foundation-Hopetoun Fund The GW Vowell Foundation Commonwealth Bank Staff Community Grants\City of Wodonga The Angior Family Foundation AH & K Johnston Family Foundation

#### **Peer support groups**

Thank you!

Bendigo Arthritis Club Cranbourne Arthritis Support Group Latrobe Valley Self Help Arthritis Group Packenham Arthritis Self Help Group Warragul Arthritis Self Help Group Moe/Narracan Arthritis Self Help Group East Bentleigh Arthritis Support Group Healesville Arthritis Self Help Support Group

#### Organisations

All Souls Opportunity Shop Beta Sigma Phi-Vic Incorporated Ritchies Supermarkets Kandooit Creatively DLA Piper K & L Gates Ryan Carlisle Thomas Lawyers

# Report of the Treasurer



In 2013 The Arthritis Foundation of Victoria (The Foundation) continued its focus on investing for the future by continuing its concentration on program service reviews and research activities while reinforcing core and specialist capacities in critical areas. At the same time Income was stable in the raffle and appeals areas.

The past year was the second year of a three year program designed to strengthen the Foundation's service provision and to broaden the scope of the Foundation's income sources and to this end significant progress was made in laying foundations in the areas of corporate giving and grants.

The Foundation experienced a reduction in total reserves in the year of (\$245,994), which comprised the following major elements:

- Deficit on operations of (\$744,731) which was largely due to increased investment, as stated above
- Interest and dividends received totalling \$145,469 from funds designated for unrestricted use
- Interest and dividends received totalling \$161,921. These were derived from funds designated for Specific Purpose use
- Specific Purpose Expenses (\$219,589)
- Net increase in the value of the Foundation's share portfolio of \$410,936.

The Foundation also provides services under the name Osteoporosis Victoria. Revenue received through activities marketed in the name of Osteoporosis Victoria is included in the revenue of The Foundation. Similarly, expenses incurred in the name of Osteoporosis Victoria are included in the expenditure of The Foundation.

The organisation attempts to balance its investment portfolio in a manner which provides security and protection against inflation. To this end it invests approximately half of its cash which is not required for operational purposes in Government Guaranteed Term Deposits. In order to offset the impact of The organisation attempts to balance its investment portfolio in a manner which provides security and protection against inflation.

inflation and low interest rates the Foundation also invests in high yielding "blue chip' shares. As part of this strategy the Foundation invested approximately \$500,000 in bank stocks during the year. The Foundation has no direct exposure to mortgage backed securities or investments in complex securities, listed or unlisted.

The financial result for 2013 reflects the second year of the three year plan to commit additional expenditure aimed at securing its financial and operational sustainability in the longer term.

Jim Dixon FCPA Honorary Treasurer

# Statement of Comprehensive Income

#### Arthritis Foundation of Victoria Statutory Financial Statement of Comprehensive Income For the Year Ended 31 December 2013

	Note	2013 \$	2012 \$
Revenue from rendering of services	5	3,784,990	3,910,128
Revenue from sale of goods		81,755	90,962
Other income	7	254,901	111,364
		4,121,646	4,112,454
Development and Business Services expenses		(2,239,450)	(2,037,834)
Training and Information Programs expenses		(2,185,100)	(2,012,682)
Policy and Research Unit expenses		(256,129)	(257,564)
Administration expenses		(185,698)	(228,244)
Operating surplus/(deficit) before finance, specific purpose income/ expense, recognition of land as commitee of management, and other comprehensive income and expenses		(744,731)	(423,870)
Finance income	6	145,469	187,057
Operating (deficit) surplus before specific purpose and other comprehensive income/expense		(599,262)	(236,813)
Specific purpose income / (expense)			
		101.001	470.047
Specific purpose revenue		161,921	178,817
Specific purpose finance income			
Specific profit / (loss) on sale of shares		-	46,869
Specific purpose expenses		(219,589)	(207,230)
Specific purpose shares and cash returned to trustee		-	(203,943)
		(57,668)	(185,487)
Operating (deficit) / surplus for the year before other comprehensive income and expenses		(656,930)	(422,300)
Other comprehensive income Net gain on valuation of land and buildings Net change in fair value of available for sale financial assets		410,936	264,474
Reversal of previous fair value adjustments of available for sale financial assets disposed of during the year	1(a), 17		(62,233)
Other comprehensive income / (deficit) for the year		410,936	202,241
Total comprehensive income for the year		(245,994)	(220,059)
		(210,004)	(220,000)

The statement of comprehensive income is to be read in conjunction with the notes which appear in the full 2013 financial statements.

Arthritis and Osteoporosis Victoria is the state's peak body for people living with over 150 musculoskeletal conditions. In 2013, there were over 1.5 million Victorians and 6.1 million Australians living with MSK.



## Here are some MSK conditions:

Achilles tendonitis Adhesive capsulitis (frozen shoulder) Adult-onset Still's disease Ankylosing spondylitis **Back problems** Baker's cyst Behçet's syndrome Bursitis Carpal tunnel syndrome Charcot's arthropathy Chondromalacia patellae Churg-Strauss vasculitis **CREST** syndrome Crohn's disease De Quervain's tenosynovitis Dermatomyositis Diffuse idiopathic skeletal hyperstosis (DISH) Discoid lupus erythematosus Drug-induced lupus erythematosus Dupuytren's contracture **Ehlers-Danlos syndrome** 

Felty syndrome Fibromyalgia Freiberg's osteochondrosis Giant cell arteritis Gout

Henoch-Schönlein purpura Juvenile dermatomyositis Juvenile idiopathic arthritis

- Pauciarticular-onset arthritisSeronegative polyarticular
- arthritisSeropositive polyarticular
- arthritisSystemic-onset arthritis
- Enthesitis-related arthritis
- Psoriatic juvenile arthritis

Kawasaki disease Kienböck's disease Lateral epicondylitis ('tennis elbow') Low back pain Medial epicondylitis ('golfer's elbow') Mixed connective tissue disease and overlap syndromes Osgood-Schlatter's disease Osteoarthritis Osteomalacia Osteonecrosis Osteoporosis Paget's disease of bone Palindromic rheumatism Perthes' disease Plantar fasciitis Polyarteritis nodosa Polymyalgia rheumatica Polymyositis Pseudogout Psoriatic arthritis Raynaud's phenomenon Reactive arthritis Rheumatoid arthritis Ross River and Barmah Forest virus Rotator cuff disease Sacroiliitis

Sarcoidosis Scheuermann's disease Sciatica Scleroderma Septic arthritis Sever's disease Sjögren's syndrome Spinal stenosis Spondylolysis Systemic lupus erythematosus (SLE) Takayasu's arteritis Tarsal tunnel syndrome Temporomandibular joint disorders Trigger finger (flexor tenosynovitis) Ulcerative colitis Vasculitis Wegener's granulomatosis

## Arthritis and Osteoporosis Victoria

263-265 Kooyong Road Elsternwick 3185 PO Box 130 Caulfield South 3162 Phone: 03 8531 8000 Toll free: 1800 011 041 Fax: 03 9530 0228 Email: afv@arthritisvic.org.au Website: www.arthritisvic.org.au



Phone: 13 14 50



ABN: 26 811 336 442

