

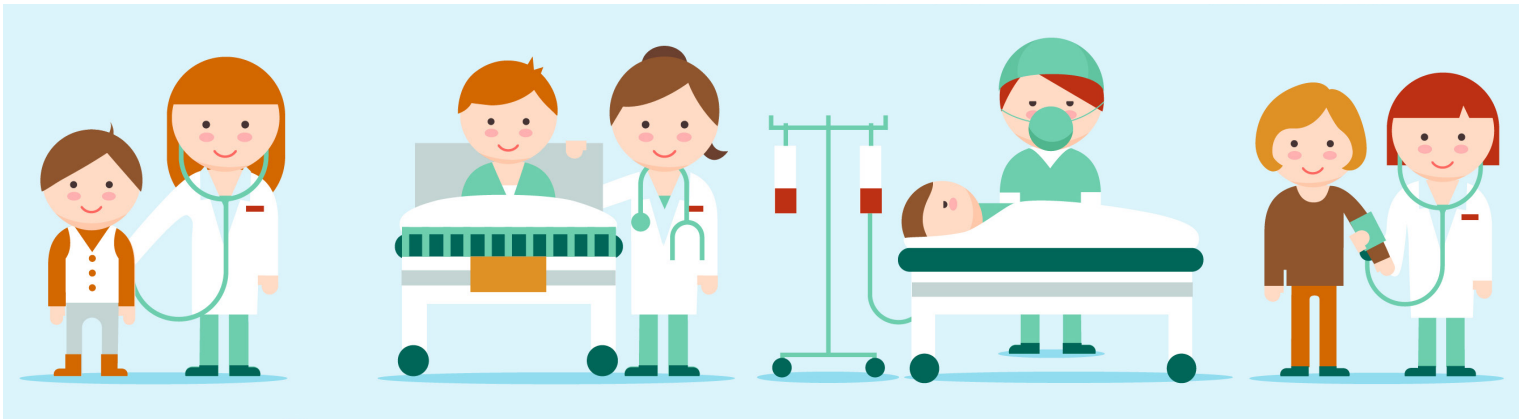


INTERNATIONAL SOCIETY FOR OTITIS MEDIA

APRIL 2016

Newsletter

#6



Patient and Public Involvement

The patient is at the heart of what we do, clinically or scientifically. Yet historically patients have rarely been given a voice in our endeavours. To better direct our efforts we want them to tell us how otitis media affect them in their daily life, what symptoms and sequelae are the most troublesome, and which clinical or research questions they want answered. There has certainly been some move in the right direction in recent years. Many research funding bodies ask for evidence of patient and public involvement (PPI) in grant applications, and in the clinical world, patient representative groups are springing up.

This issue of the newsletter focuses on our patients. We have Lori from the US telling us how acute OM affects the life of her child and the family. Steve from the UK tells us what it is like to live with chronic recurrent OM. In low and middle-income countries treatment of ear disease can

be difficult or impossible, due to difficulties with access, and a lack of infrastructure and training. Sandra relays the story of Ramesh, a child with chronic suppurative OM living in Nepal, and Davy relays the story of Sophon, an adult with cholesteatoma in Cambodia. I am currently working alongside Davy in Cambodia, and the prevalence and severity of disease here reminds me of the task ahead of us when we consider OM as a global health problem.

We complete our patient focus with an article from Aneeka Degun on the value of PPI involvement in ENT research. And we have updates from our president, secretary, and treasurer.



Mahmood Bhutta
Editor, ISOM Newsletter
Children's Surgical Centre,
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President's report

It is my pleasure to provide you with an update from the President of ISOM. As you all know, there is no ISOM meeting this year but the preparations for the 19th Recent Advances in Otitis Media Meeting at the Gold Coast in Australia in 2017 are in full swing. The local committee is doing an outstanding job so we can look forward to a fabulous scientific meeting in an exciting part of the world.

However, that does not mean that the ISOM Board is not busy. As the Board members are from all parts of the world, our Board meetings are done via conference calls. Due to the time difference some of the board members have to get up in the middle of the night to join the meeting. At the present time most of the Committees are complete but there are openings for those who are interested - please contact me.

One of our priorities is to improve the ISOM website so it can become a reference point for all the ISOM members - a place to get information about the latest updates regarding treatment and research in otitis media as well as to promote collaborations between different groups. You are all welcome to participate in this endeavor by sending us ideas and suggestions about how it would be useful for you. You can also contribute by sending us information about new important research that you think should be posted on the website.



Tania Sih
President ISOM
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My Story Hem Sophon, Cambodia



I'm 48 years old. My older sister tells me that I've had discharge from my right ear from when I was an infant. I remember the discharge getting really bad when I was a teenager, especially during the wet season, and then I started to also get earache, and sometimes a bit of dizziness. For as long as I can remember I've not been able to hear anything in my right ear.

One day in 1987 I went swimming and then after that I suddenly developed weakness of the right half of my face. My parents took me to a traditional healer, who put steamed beef on my face. It didn't

really help, and the right side of my face has been weak for nearly 30 years now.

A few years ago I started to think I should see a doctor about my ear discharge, but I had to travel five hours to see the only specialist ear surgeon in Cambodia, and when I saw him I wasn't confident he could help. Then a few months ago the ear pain got really bad and I got an abscess behind my ear. I heard that luckily there was now a visiting foreign surgeon in Cambodia. He operated on and fixed my ear. He told me that I had a "cholesteatoma" that had

destroyed almost all of the ear bone, including onto the lining of my brain, into my saliva gland, and around the nerves of hearing and the nerve of my face.

I am grateful for the treatment I received, and I hope I will have a long life.

Story relayed by Davy, ENT Surgeon, Children's Surgical Centre, Cambodia



My Story Ramesh, Nepal



My name is Ramesh and I'm 12 years old. I live in Myagdi District (Rahnbagwati Village) which is about 8 hours away from Pokhara. My mother died 2 years ago, she was dumb. My father works as a labourer, he is deaf. I live with my grandmother. When I was 2 years old I got an ear infection and since then I was suffering pain every day. Especially in the morning it was very difficult and the pain lasted up to 1 hour. I didn't go to the hospital because we had no money and didn't know how bad the infection was. In the last 1 ½ years the pain got worse and my ear started to smell.

My family, friends and teacher realized there is something wrong with my ear. Some were talking about me and avoided me. That made me sad. My grandmother suggested going to see a doctor. There's a small health post ½ hour away from my home and I went to see the health assistant in this clinic. He gave me some medicine for the pain which helped a lot. But the infection was still there and later the right side of my face began to droop. My whole family then got very worried. We went to the local hospital in Myagdi which is 4 hours away from my home. But they couldn't help me there

and sent me to Pokhara. I went to the INF Ear Hospital and Training Center where they found a problem with my right ear (chronic suppurative otitis media). I then got admitted and had an operation (mastoid exploration). After the operation my face and hearing was better."



Sandra Eisner
Audiology lead,
INF Ear Hospital, Nepal

Chronic ear disease is a high and growing burden worldwide with millions of people being affected. It can easily be treated and prevented but when neglected, chronic and recurrent ear infections can lead to serious complications. Furthermore people experience stigma, fear and barriers in their education and work. In order to be detected and treated at an early stage people would need to be aware of the consequences of ear disease and have sufficient access to health care facilities. Especially developing countries in particular the majority of the population have little knowledge of ear disease or access to healthcare. Therefore ear disease is usually left untreated.

I met a little boy at the INF Ear Hospital in Pokhara/Nepal and this is his story: Ramesh' story stands for thousand other people in Nepal and demonstrates the current situation. Raising awareness within the population, delivering community based ear care programs, establishing health care facilities and training professionals would be strategies to reduce the impact ear disease has on Nepal and its people. The INF Ear Hospital and Trainingcenter in Pokhara was opened in November 2015 and is trying to meet these needs by treating and education people.

My Story Lori N, USA



My daughter was first exposed to viruses at about 6 months old when she started daycare. At this time we started a monthly cycle of contracting a respiratory virus that would lead to congestion and eventually cause an ear infection. An antibiotic would be prescribed which would cause terrible

diarrhea and diaper rash and was always a huge struggle to get her to take due to oral sensory issues. No sooner than the antibiotic was finished we would start the cycle again. During this time it was difficult to juggle work, doctor appointments and time off of work. It was also very difficult on Kaitlin/us with trying to introduce new foods as she began to be very leery of trying anything new due to her aversion to the oral antibiotics.

In February of 2014, about 5-6 months after this started, we began discussing ear tubes with her pediatrician. I was semi reluctant to have a 10 month old undergo a procedure but being a pharmacist myself I was very concerned with her antibiotic exposure at an early age. We decided it was in

her best interest to have the ear tubes placed.

That was two years ago and we have only had two ear infections in that time. One due to ear wax blocking the tube (only required antibiotic ear drops) and one recently as the tubes have fallen out. The ear tubes were of great benefit and drastically reduced my daughter's antibiotic exposure.

My Story Stephen Jennions, UK

RRRRRRRRIIIIIIINNNNNNGGGGGG-GIIIIIIINNNNNNGGGGGG!!!!!! This (increased tinnitus) is the first thing that tells me another bout of otitis media is brewing. I sigh, because it means a minimum of weeks of discomfort and reduced hearing. Since it almost always develops into chronic suppurative otitis media, this will also include the unsightliness of otorrhoea draining to the outside of the ear, as well as polyp formation in the ear canal which usually causes episodes of spontaneous haemorrhage.

These days, our kind friends at Glaxo have stopped manufacturing Otosporin here in the UK and my last few bouts have been driven by streptococcus, a very common, but multi-antibiotic resistive little bugger! That means frequent trips to the Royal (Royal National Throat Nose and Ear Hospital London) for

a course of micro-suction after a few weeks of topical application of various antibiotic and steroid drops fail to clear the mess up (the first line of treatment with drops is almost always fruitless because they are not the right ones, but such is the protocol I must adhere to). After a period of time has passed, the bacteria are finally vanquished and I can go back to a more normal life hoping that an ordinary activity like gardening does not inadvertently introduce bacteria into my ear again and that I may have a decent gap between infections.

This has an enormous impact on my life. Although I am lucky enough to be able to tolerate tinnitus well, the onset of yet another infection is akin to being presented with a mountain to climb without the correct equipment. Perhaps the most arduous part is that although

I know immediately the infection has taken hold (probably before a swab could even be taken), I know it will be many weeks until it is resolved and it will not be done efficiently. Knowing about the impending discomfort and unsightliness which I am to suffer each time is wearying, to say the least. It is a real treadmill to have to be on.



A word from the Secretary



Joseph E. Kerschner
Secretary, ISOM
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For the first time in ISOM's existence we are in an interesting time in which we are neither forming the new organization, writing new Bylaws or planning for a meeting just around the corner!! It is a welcome respite from the flurry of activity over the past few years. However, your Society is not sitting idle. We continue to build on our committee work, have continued with Executive Commit-

tee and Board meetings and have updated materials on the website. Please take a moment to look at the website if you haven't been there in a while. Particularly Dr. Vedantam's Education Committee has added some nice new materials which can be found at: <http://www.otitismediasociety.org/education-committee.html>

We are continuing to collaborate

with our Australian hosts for the next ISOM meeting in June 4-8 on the Gold Coast. Additional details can be found on the ISOM webpage at:

<http://www.otitismediasociety.org/2017-symposium.html>

Please let me know if you have any additional suggestions for the website or anything else for our wonderful Society!!

A word from the Treasurer



Margaretha Casselbrant
Treasurer, ISOM
University of Pittsburgh
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Dear members of ISOM. It is amazing to me that this young Society already is publishing the 6th ISOM Newsletter. We are indebted to Mahmood Bhutta the editor and his wife Anki who is doing the outstanding graphic design. This issue is focusing on otitis media from the parent's and patient's perspective. The Newsletter is a great way for us to stay in contact between the meetings.

It is an honor for me to continue to serve as the ISOM Treasurer. I am responsible for managing the Society's funds as well as collecting the membership dues. I want to thank all of you who have already renewed your ISOM membership for 2016. For those of you who have not yet renewed your membership, please do so as soon as possible.

You can either go to the ISOM website www.otitismediasociety.org and pay online or you can send a check (M Casselbrant MD, Children's Hospital of Pittsburgh, 4401 Penn Ave, Pittsburgh PA 15224). The fee for full membership is \$150 and for students \$75. The deadline for the yearly renewal of the membership is April 30.

Our Society continues to grow with more than 100 charter members but I do urge all of you to encourage your students, trainees and colleagues to become members of ISOM. Membership information can be found on the website www.otitismediasociety.org which is presently being updated.

Patient and Public Involvement (PPI) - improving the value of research

Recognising that clinical research designed by professionals often failed to change practice, the UK National Institute for Health Research (NIHR) has set the standard in involving patients and their families as active partners in research. Supported by the national advisory group INVOLVE (www.invo.org.uk), researchers are encouraged to work with patients and their families throughout the research process, ensuring that research is relevant and focuses on questions and outcomes that matter to them.

Within our evidENT team, we held parent focus groups and interviews to guide our research in children with recurrent otitis media. By reviewing our research proposal, parents guided us in how best to design the practicalities of the study and which outcomes to use. As researchers, we proposed the number of GP visits for otitis media as the primary outcome.

Parents however felt that that was not their main concern. They wanted treatment to improve the day to day consequences of otitis media, such as problems sleeping, going off food and time missed from day care or school for their child and from work for themselves. We therefore included these more holistic outcome measures within our study. Parents also highlighted their busy family schedules as a hurdle to take part in our research, so we organised follow up visits



at flexible times including early evenings and weekends.

This is just one example of the power and impact of PPI, ensuring research is meaningful to the communities that we serve.



Aneeka Degun
PPI Lead, evidENT team
(UCL Ear Institute), London

Save the date!



19TH INTERNATIONAL SYMPOSIUM ON RECENT ADVANCES IN OTITIS MEDIA

Gold Coast Convention and Exhibition Centre,
Gold Coast, Australia **4-8 June 2017**



INTERNATIONAL SOCIETY FOR
OTITIS MEDIA

Visit the website to register your interest! www.otitismedia2017.com

The International Society for Otitis Media extends a warm invitation to join us at the 19th International Symposium on Recent Advances in Otitis Media (RAOM) 2017. RAOM 2017 will be held at the Gold Coast Convention and Exhibition Centre at the Gold Coast, Australia from 4-8 June 2017.

The Symposium will bring together international and Australian experts to share knowledge of recent science and clinical practice for otitis media. The program will address diagnosis, prevention strategies, treatment, epidemiology, pathogenesis, microbiology, immunology, complications and sequelae, animal models and otitis media in Indigenous and high risk populations. The program will include keynote and concurrent oral presentations, poster sessions, a trade exhibition, as well as social events.

We look forward to welcoming you to the Gold Coast in June 2017!

Visit the Symposium website for more information: www.otitismedia2017.com



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