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FREE
8 PAGE HEALTHY HOME GUIDE

Roger Honeybun
– One man, one road, one cycle

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asthma NEW ZEALAND THE LUNG ASSOCIATION
THE NZ JOURNAL OF RESPIRATORY HEALTH
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Roger Honeybun
'One man, one road, one cycle' – Page 14
Photo by Steven Neville, ASP Photography.

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Unitec NEW ZEALAND Te Whare Wānanga o Wairaka

asthma NEW ZEALAND THE LUNG ASSOCIATION

Applications are now invited from registered nurses wanting to enrol in the Asthma New Zealand/Unitec Asthma Nursing Course for February 2010 and COPD Nursing Course for April 2010. The programmes are offered by distance learning. The primary aim of the Asthma and COPD Nursing Courses are to provide nursing health professionals with a high level of evidence-based asthma and COPD knowledge that promotes best practice and is consistent with national policy.

Since the commencement of the Asthma and COPD Nursing Courses, 776 nurses have enrolled over 28 intakes. Many applicants had not undertaken any additional study since completing their nursing training, which may have been years before. However, most find the courses to be a challenging but thoroughly enjoyable learning experience that is within the grasp of any competent nurse practitioner.

Asthma New Zealand in association with Unitec New Zealand offers these courses within the Bachelor of Nursing Programme. Asthma Nursing Course is a level 7 course and attracts 24 credits. COPD Nursing Course is a level 7 course with 12 credits. A grant towards the cost is available for registered nurses.

For an enrolment form for the first Semester please contact:

Ann or Swarna
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P O Box 67- 066, Mt Eden, Auckland 1349
Phone: 09 623 0236 – Ex 804
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Email: annw@asthma-nz.org.nz or swarnah@asthma-nz.org.nz

The closing date for first Semester enrolment is
30 January 2010 for Asthma 15 March 2010 for COPD

Upcoming events and courses

1 DAY 'NEAT' ASTHMA COURSE FOR REGISTERED NURSES
9 September 2009
3 March 2010

½ DAY COPD COURSE FOR REGISTERED NURSES
7 October 2009
22 April 2010

- **Friday 6 November 2009** – *Asthma Auckland Golf Day at Redwood Park Golf Course.*

asthma NEW ZEALAND THE LUNG ASSOCIATION

ONE MAN, ONE ROAD, ONE CYCLE
13-21 March 2010

Further enquiries for any of these events phone
09 630 2293

World Asthma Day 2009

Message to Readers

Dear Readers,

The major news of the month is the request from a number of societies (both existing and "in recess") who have asked Asthma New Zealand – the Lung Association (inc.) to develop a "Branch-based" system across New Zealand. This presents many challenges. It is obvious that a branch-based system would be more successful and attract more funding than the current "stand-alone" societies across New Zealand. Asthma New Zealand is working with societies to ensure that there will be a smooth transition to this "Branch-based" model. A memorandum of understanding has been developed to ensure that the process is "Branch-based" in a planned way, with set objectives in terms of what we are hoping to achieve. The branch-based system must be "non threatening" and very inclusive. The current Asthma New Zealand – the Lung Association Board has representatives from Auckland, Rotorua, Wellington, Christchurch, Timaru and Invercargill; a good mixture!

It is hoped that a National Based system would attract greater financial support from the Ministry of Health. National Standards will be of a higher standard than what may be the current situation. I shall continue to work with Societies to achieve these ends.

Sincerely

Gerry Hanna
Executive Director
Asthma New Zealand – the Lung Association

Asthma medication – a sticky subject

Compiled by Ann Wheat

Why do people with asthma not use their medications as prescribed? What are the fears that many people have about medication and is there anything that can be done to help?

Many people with asthma report that their preventer use (e.g. Flixotide, Beclazone or Pulmicort) is in the moderate to high moderate range but unfortunately this is not supported by the amount of medication that is dispensed by pharmacists (Ivana, Birnbaum, Hsieh, Yu, Seal, van der Molen et al, 2008).

When treating asthma the goals for good control are symptoms less than twice a week in the daytime, no awakening at night from asthma, reliever use less than twice a week, normal or near normal lung function and no exacerbations. Many people with asthma therefore often live with symptoms that they consider normal. So why is this, when asthma can be well controlled?

Influencing Factors for Compliance

According to Gillissen, Wirtz & Juergens (2007), there are many factors that play a part in poorly controlled asthma and they can be arranged into two categories, the doctor factor and the patient factor.

When looking at the *doctor factors*, some of the diagnostic and therapeutic factors that may affect medication compliance are:

- The possibility of a wrong diagnosis
- A too complicated medication regime, (for example too many inhaler devices)
- The length of time between visits, (for example over the recommended three month review visit)

Looking at the *patient factors* some of the factors that could be responsible are:

- Disbelief – people do not use medications when they have symptoms as they see them as unnecessary, they are afraid of side effects and they do not believe the symptoms are important.
- Lack of knowledge and/or understanding such as poor understanding about asthma, the need for ongoing medication, erroneous beliefs about severity, asthma duration and its causes and consequences.
- Barriers related to income such as the inability to obtain all medications prescribed
- Gaps in knowledge and self-management such as using alternative treatments
- Concern about adverse effects from long-term medication use such as the use of inhaler corticosteroids
- Concerns about dependence, peer stigmatism and parent-child conflicts such as parents reminding young people to take medication all the time
- Complacency due to well controlled asthma and the need to continue medication
- Technique problems such as the incorrect use of devices
- Risk behaviours such as smoking cigarettes, cannabis use or drinking alcohol

How can medication adherence be improved?

The one most essential way to improve adherence issues is good communication. This is not only from the health professional's point of view but also from the point of view of the person with asthma. Health professionals (such as general practitioners, practice nurses or asthma nurse educators) rely on patients to tell them about symptoms, their wellbeing, concerns and satisfaction with their treatment. **It is essential that patients advise their health professional of the impact that asthma is having on their lives**. Without this knowledge it is impossible for the health practitioner to allay people's fears about medication, review written action plans, reinforce messages of medication use, device use, correct care of inhalers and to alter treatment as required. Patients rely on the health professional to monitor their condition, provide correct or appropriate treatment and explain their asthma management. It is also important for the health professional to be able to check correct inhaler techniques, symptom diaries or peak flow meters so as to accurately obtain a picture of asthma control since the previous visit.
One of the best ways to improve adherence is to ensure a simple treatment regimen and to ensure that the patient has a written action plan so as to know the treatment regimen they are currently on. This written plan should be updated once a year.

The use of multiple inhalers or types of inhalers will reduce the level of long term medication use. It is important to discuss with the health professional what medications patients are on and if there is a better way of taking them. For example, if using a preventer and a symptom controller for over three months, then is it possible to use a combination medication. Research has shown that reducing the number of inhalers does indeed help to increase adherence. The other important factor when using inhalers is that the inhaler is used correctly. It is therefore very important that patients are educated in the use of their inhalers. This means that the health professional has to know about the guidelines on asthma control and how to use the different inhalers correctly themselves so that that they can demonstrate to the patients and re-evaluate their technique at every visit.

Conclusion

Having a good doctor/patient relationship is therefore imperative to help with good adherence of medication. Health professionals should:

- Provide sufficient information about asthma and its treatment. The messages given should be consistent no matter which health professional is giving the information, so patients are not receiving mixed messages.
- Adequate discussion between health professionals and patients is essential so that trust can be built up, patients feel part of the jointly agreed goals including the writing of the management plan and that the patient feels able to clarify anything that they do not understand.
- Ensure that there is a simple administration regime.
- Try to remove any barriers that may occur which prevent patient contact.
- Refer on patients as necessary to the appropriate person to assist patients with understanding of their condition.

Remember, it is not just health professionals who play a role in asthma control, but it is people with asthma themselves who must be prepared to advise others, discuss and take an active role in their own management.

References:
Gillissen, A., Wirtz, H. & Juergens, U. (2007). Patient and Physician Factors Contributing to Poor Outcomes in Patients with Asthma and COPD. Disease Management Health Outcomes: 15 (6): 355-376
Ivanova, J.I., Birnbaum, H.G., Hsieh, M., Yu, A.P., Seal, B., van der Molen, T., Emani, S., Rosiello, R.A., & Colice, G.L. (2008). Adherence to Inhaled Corticosteroid Use and Local Adverse Events in Persistent Asthma. The American Journal of Managed Care: 14 (12) 801-809

Asthma lobby yet to heal breach

New Zealand Doctor Latest News – 29 July 2009

Jodi Yeats | Senior Journalist

Despite a move to invite regional asthma societies to join forces and lobby for funding, Asthma New Zealand will not be extending the hand of friendship to the Asthma and Respiratory Foundation.

Asthma New Zealand is writing to all regional asthma societies inviting them to form a branch-based society.

When Asthma New Zealand was set up in 1997 it aimed to set up such a system, but found many societies valued their independence and were suspicious of an Auckland-based organisation, secretary/treasurer Gerry Hanna says.

However, since then local asthma societies have struggled to get funding under the DHB system and around 14 have been forced to go into recess. Some of these groups are now interested in joining Asthma New Zealand, Mr Hanna says.

Asthma New Zealand is proposing they sign an MOU, as a first step, and then adopt nationally standardised computing, database and fundraising systems.

This will help the societies apply for DHB funding as it will assist with the reporting requirements, he says.

Eventually, the aim is to apply for funding from the Ministry of Health rather than continuing to deal with regional DHBs.

All the New Zealand societies are members of the Asthma and Respiratory Foundation. Asthma New Zealand is suggesting they retain their membership and the associated access to funding, Mr Hanna says.

Asthma New Zealand broke away from the foundation in the late 1990s because of a rift over the foundationís not-for-profit subsidiary Airflow Products, which sells Salamol.

Asthma New Zealand sees the Foundation's involvement in running a business selling a drug, which contains alcohol and is used by children, as a conflict of interest.

Asthma and Respiratory Foundation executive director Jane Patterson says Salamol is the biggest selling salbutamol in the US and contains only a very small amount of alcohol.

In 2005 the New Zealand Paediatric Society stated that: *"children should not be unnecessarily exposed to alcohol."*

Goal setting in asthma management – a patient's perspective versus a professional's

Many times as educators we are sent out to assist a patient/client with the on-going management of existing or newly diagnosed asthma.

Generally from a health care professional's perspective, success is usually measured by the client achieving as close as possible to their predicted 'peak expiratory flow' – they present as a person who does not have the symptoms of asthma.

Seldom do we ask our clients what they want from successful management of their asthma as we are usually completely focussed on the objective measurement of asthma and not the subjective experiences of the person with asthma.

What do we mean by 'Goal setting'?

Definition of a goal would be something you could be expected to achieve in 3 to 6 months – and importantly needs to be something that you have jointly agreed as being realistically achievable.

A question that we as health professionals should be asking our clients is:

Is there something that you would like to do that your condition (asthma) prevents you from doing, such as walking the dog, tramping or walking to the diary?

It is important that you don't try and reach all your goals at once – you would not be able to go from couch potato to an Olympic runner in one week – break goals down into smaller achievable steps and build up.

These one-week steps are called action plans.

For example:

One action plan could read: I will remember to take my preventer at the same time every day for the next week – What steps could I take to make sure this happens?

1. Write a reminder on a calendar or in a diary or set a daily reminder on your mobile phone or ask a friend to remind you.

2. What would prevent you from taking your preventer daily? – Maybe if it is not in plain sight in the morning – so put it in a place you go every morning – the bathroom by your toothbrush or by your car keys or even leave a reminder in the form of a note on the front door above the lock so you see it before you go out to work in the morning.

Action plans should be **specific**. Not, "I will use my blue puffer less",

but "I will remember to take my preventer daily at 7 am and 7 pm without fail" *(and thereby will have less symptoms and require less symptom reliever).*

Sounds too simplistic?

Really – It needs to be to be ***realistic...***

Action plans need to be **realistic** to have any hope of a '***buy in***' by the client/patient.

For example: ***Not***, "I will run five miles", if you haven't exercised for years, but "I will walk around the block after dinner, 4 days per week, with my dog. " Start slow and build up.

It's about behaviour and not results. *Not* "I will ensure that I maintain my peak flow at above 85%", ***But*** "I will treat ***all*** my asthma symptoms with my symptom reliever and record its use in my symptom diary".

You should be very confident about your action plans – ask yourself how confident you are on a scale of 1 to 10 (10 means you can do it – anything less than 7, then you need to go back and brainstorm with family and friends to find out how you can raise your confidence).

A recent study by the Faculty of Pharmacy, University of Sydney, 2006, found that most patients scored low on their priority to achieve compliance with action plans which covered "assessing asthma severity, achieving best lung function (PEFR), developing an asthma action plan and educating and reviewing their asthma management."

More highly scored were to: "maintain best lung function, identify and avoid triggers, and optimise their medication program. The study concluded that patients with asthma ***set personal goals*** which can ***differ to clinical treatment goals***.

Clearly to achieve any success in the control of your asthma any goals which are set must contain within them action plans which are specific, realistic, achievable, about behaviour and not just results.

I would challenge you all to question yourselves closely about what your personal goals are in your pursuit of the good control of your asthma – ***you may need to make sure it's not Mount Everest that you are choosing to climb in a weekend!***

David Halewood RN
Asthma Nurse Educator

References:
Kahawati, C., Smith, L. & Amour, C., (2008). Goal Setting by people with asthma – what do they want? Pharmacist. 27,(8): 674-678.

Asthma and Pools

Compiled by Rodd Gibbs

If your child has asthma, letting them go to a local swimming pool, could be sending them straight to hospital.

Many of New Zealand's public and school swimming pools are covered, to give all year round use. In the past health advisers have encouraged people with asthma or breathing problems to take exercise in these areas, as the humid air helps. Recent studies show however that there is a hidden gas present that can cause serious damage to people with already compromised lungs. This gas is nitrogen trichloride. Nitrogen trichloride is formed when nitrogen from sweat, body oils, and other human excretions mixes with chlorine. It collects near the water surface and is taken in as swimmers come up for air.

Since 2003, researchers have found a connection between Lung problems and indoor swimming pools. They were responding to increased rates of asthma among adults who were employed at swimming pools, as well as even higher rates in children who used these facilities. Studies found that adults who swam at these pools suffered many more asthma attacks than swimmers who used outdoor uncovered pools. As well as that, evidence came out that if the swimmers stopped swimming or moved to outside pools their asthma got significantly better.

Nitrogen trichloride has been found by Belgian researcher Alfred Bernard to weaken the protective surface of the lungs. In a study of 624 swimming pool workers there was a significant correlation between upper respiratory symptoms and their total exposure to nitrogen trichloride.

So how can you protect yourself and others from this?

Firstly ask the pool operators if they test the air in the pool area for any toxins, most pools test for water purity but not air quality. When you enter the pool area see if you can smell a strong chlorine odor. This is not a clean indicator but in fact a way of telling that nitrogen trichloride is present. If you do smell this gas tell the pool attendants. They may need to adjust the ventilation or the chlorine levels. Before entering the pool shower and encourage others to do so also. Use soap, as water alone will not take off oils and sweat. Avoid using the pools when many people are there, or after some swim meet has just finished because of increased levels of the gas.

Don't socialise in the pool area. Keep your kids away from playing in the pool complex in such places as kids play areas, as the gas can accumulate there with the reduced air flow. If possible swim out doors where the wind can blow away any chemical fumes that form.

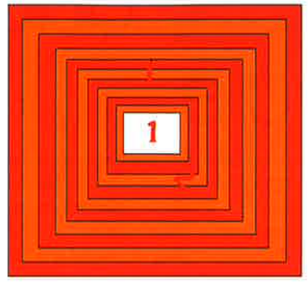
Finally if you or your child develops breathing problems during or after a swim or you find that asthma symptoms present, see your doctor and tell him or her that you may have been exposed to nitrogen trichloride at the pool.

Swimming is very good exercise and should be enjoyed. It is low impact and adaptable for all levels of fitness. So keep swimming, just look for pools that have clean air and water.

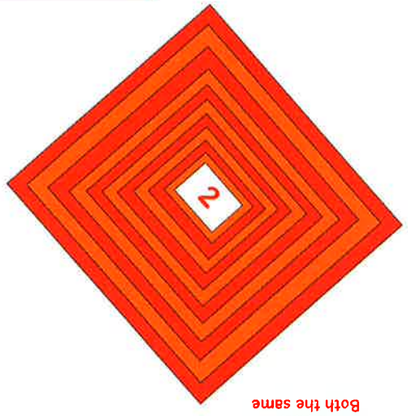
Winners of the Allerzero competition April 2009

J. Patel, Remuera, Auckland
D. Cloete, Army Bay, Rodney
M. Revell, Eastern Beach, Auckland
K. Matthews, Te Atatu South, Auckland
A. Burgess, Titirangi, Auckland

Kid's Page



Which square is bigger?



Answer
Both the same

One morning a digital clock shows readout No. 1, which is odd since it's well before noon. Nearly two hours later, the clock shows readout No. 2. Can you guess what is causing the incorrect displays?

Answer
The clock was upside down

MAGIC SQUARE

Using only the numbers **1,6,8,9** complete the square so that each row, column and diagonal add up to 24. Each number can only used once per line!

9			6
		9	
6			
1			8

Answer

9	1	8	6
8	6	9	1
6	8	1	9
1	9	6	8

MATCH THE CAPS!

Only two caps have been put on the correct bottle. Rearrange the order of the caps so that they are all on the right bottles.

Answer
The colour of the background corresponds to the cap of the same colour

One man, one road, one cycle

Asthma New Zealand were approached earlier this year by a man, Roger Honeybun, wishing to do something in the memory of his 9 year old nephew who passed away in January from an exacerbation of Asthma. He proposed to cycle 1000 kilometres along State Highway 1 on his own, to raise awareness of asthma and hoped that we would support him and offer some sponsorship or endorsement.

Originally Roger thought the ride would be a "personal challenge". However, "after thinking about it, I thought as well as taking on the cycling challenge by riding 1000 kilometres in 9 days, I could 'rattle a bucket' along the way to raise awareness of asthma and funds for Asthma New Zealand," he said.

Roger, who is a runner more than a cyclist chose to ride the length of the country simply because it was "too far to run".

"As someone who has never suffered from any sort of infirmity, I was amazed that, in this day and age, children were still dying of this incredibly common affliction," said Roger.

When he approached Asthma New Zealand to gain our permission, we were so keen and the timing was perfect as I was looking for an angle for a National Awareness Campaign for 2010 and proposed we not only support him but offered to follow him on this journey with our Mobile Asthma Clinic, and a team of Asthma Nurse Educators, offering free education and advice, in main towns along the way – 1034 kilometres in 9 days with an entourage of supporters and media in tow. A National Campaign was born!

Roger is a member of the maintenance team at Housing New Zealand and is only too aware of the scourge of asthma and other lung diseases prevalent in our community.

"This ride not only gives me an opportunity to raise awareness and funds for Asthma New Zealand but also offers people a chance to gain information and assistance by visiting the mobile clinic along the way".

We are hoping to raise as much money as possible by running a TXT Campaign during the "ride"; people will be asked to TXT a $3 donation and be offered a chance to register online for one of the amazing prizes on offer. There will be at least one prize for each of the nine days and a major prize draw at the end.

The ride is scheduled to begin on Saturday 13 March at Christchurch, finishing at Auckland on Sunday 21 March. We have had so much support for this campaign and would initially like to thank Bike Barn for their amazing contribution of Roger's bike, gear, nutrition advice and supplements from Balance. We also need to thank Bunnings Ltd for their contribution as we will be parking our bus outside their stores throughout the country, with their staff on "sausage sizzle" duty each day, perhaps raising both awareness and a few dollars as well. We have so many other sponsors coming on board and hope to recognise them all through our website and future magazines.

This campaign has the potential to have a huge impact on the community and ongoing assistance and support with research and education about asthma in New Zealand.

It will help us to empower people with asthma to take control and manage their asthma. Further supporting families to take the necessary steps for home management and in turn reduce hospitalisations and re-admissions for asthma, time off work and school.

Linda Thompson
PR / Fundraising Manager
Asthma New Zealand

ASTHMA FACTS

- Asthma affects one in four children in New Zealand.
- Asthma affects one in six adults in New Zealand.
- It is estimated that it costs the country over $1 billion annually.

ASTHMA does kill!

North & South

NEWS FROM AROUND THE REGIONS ...

World Asthma Day 2009

Westfield St Lukes

Botany town centre

Asthma Auckland staff and volunteers celebrated World Asthma Day 2009 with the release of our Breathe Easy T-shirts which were proudly sold through all Line 7 Stores and from our stalls at Botany Town Centre and Westfield St Lukes. We made our presence known at both locations offering free advice and follow up education sessions, gave out stickers, sold t-shirts and raised over $1500 for Asthma in the process. I would like to thank our fabulous group of volunteers, the staff of Life Pharmacy St Lukes and Management at both Botany Town Centre and Westfield St Lukes for making this an extremely successful day. If you missed out on our T-shirt on the day, it's not too late, just give us a call on 09 630 2293 and we'll send one out or call in and see us at 581 Mt Eden Road, Auckland.

Thanks

Linda Thompson
PR / Fundraising Manager

Gluten Free Food & Allergy Show

ASB Showgrounds Auckland 23-24 May 2009

Up to 1 in 4 New Zealanders have an allergy, asthma or intolerance. You could be one of them.

The Gluten Free Food & Allergy Show is New Zealand's only expo dedicated to bringing ideas and solutions for allergy and food intolerance issues.

This year's Auckland Gluten Free Food & Allergy Show was a huge success, Asthma Auckland – New Zealand had a stand there for the second year running and we were visited by literally hundreds of people on both days and received over 25 follow up home visits. It was a great opportunity for us to raise awareness, educate and provide simple techniques to help those affected by asthma to understand and manage their condition. We would like to thank Fujitsu for sponsoring this stand and therefore the community, assisting us in providing our free training and education sessions to the wider community reducing hospital admissions, days off school and reducing the burden on our health system.

Linda Thompson
PR / Fundraising Manager

Introducing... Elaine Murray

Elaine trained to become a Registered nurse Auckland Hospital. After receiving her registration she worked for the Selwyn Foundation in Point Chevalier, Auckland, and later as a Charge Nurse for them for many years.

After leaving there she became the Manager of the Dementia Unit and Day Care which was most interesting and rewarding.

For the last 18 months she has worked for an Auckland Allergy Specialist, assisting with an Immunotherapy Programme.

Elaine is looking forward to learning more about asthma and passing on her knowledge through our education programmes throughout Auckland.

She currently lives in Auckland is married with two children and has one grand-daughter.

Her interests include golf, tennis, reading and family.

Some of the things Asthma Canterbury have been doing ...

COMMUNITY LINK EXPO

On 20 May, Asthma Canterbury participated in a Health Expo held at the Community Link Office in Linwood. Other agencies who attended included Family Planning, Workbridge, St Johns, Bipolar Support, Oasis Centre for Problem Gambling, Smokefree, ACC, B4 School Nurses, Immunisation Nurses, Diabetes screening. Despite the terrible weather – (torrential rain and hail storms!) we had a steady stream of people visiting, many of whom left their contact details for follow up one on one consultations.

KAIAPOI CROSSING PHARMACY CLINIC

To celebrate Asthma Awareness week in May, Kaiapoi Crossing Pharmacy requested an Asthma Clinic at their pharmacy. Moira and Belinda attended the first day with a stand promoting Asthma Awareness and small group workshops on the Use of Devices and Inhalers. The following week, Moira returned for individual consultations with Pharmacy customers. This was a great way for us to take our services out into the community.

EASTGATE ENERGISE 2009 EXPO

Asthma Canterbury were invited to be participants in the Energise 2009 Health Expo at Eastgate Mall on 16th and 17 April which was organised by the Canterbury District Health Board. This was a great opportunity to promote our services as there were lots of people in the mall over these two days.

NEW PROGRAMME DEVELOPED

To complement the STOP, TAKE, TELL programme we currently offer to Years 2-4 in schools, we have now developed the BEN & BAXTER programme for new entrants and Year 1 children. BEN & BAXTER is an interactive session featuring our very popular Baxter Bear and a super-sized story book. Using this we aim to increase awareness of asthma in these young students.

Alpha-1 Antitrypsin Deficiency – Do you have it?

Compiled by Debra Leutenegger

How was Alpha-1 Antitrypsin Deficiency discovered?

The first patients with this condition were reported by Laurell and Erickson in Sweden, 1963. Women and men are affected in equal numbers. This condition is found in all ethnic groups; however, it occurs most often in whites of European ancestry. The name of this disease originated from a deficiency of the serum antiprotease, originally called AAT. Fortunately, not every individual with AAT deficiency develops clinically significant disease.

According to Prof. David Lomas "the Z allele is believed to have arisen from a single origin 66 generations, or 2,000 years ago after the divergence of the races. The high frequency in Southern Scandinavia suggests that the mutation arose in the Viking population when they populated mid- or northern Europe and before their migration to Scandinavia".

What is Alpha-1 Antitrypsin deficiency?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic (or inherited) condition. The condition is caused by an abnormal alpha-1 protein that is produced by the liver and helps to protect the lungs.

The deficiency may result in serious, chronic lung disease and/or liver disease and can affect different age groups (children and adults).

How do I know that I have Alpha-1?

Often Alpha-1 can be misdiagnosed as asthma, bronchitis, emphysema or Chronic Obstructive Pulmonary Disease of unknown cause. Symptoms may include a chronic cough, shortness of breath, recurring respiratory infections, and abnormal liver test results.

Alpha-1 can be diagnosed by having a simple blood test and is recommended for people who have relatives who have been diagnosed with Alpha-1, if there is a family history of emphysema (whether a smoker or non-smoker) or symptoms are present.

The test measures alpha-1 antitrypsin levels in the blood. People with two healthy copies of the alpha-1 gene produce the most alpha-1 antitrypsin and people with no copies of the gene at all produce the least.

An individual's genetic makeup (genotype) combines with environmental factors to determine their phenotype.

PHENOTYPES

MM (two normal copies)
MZ (one normal copy, one deficient copy)
SS (two marginally deficient copies)
SZ (one deficient copy, one marginally deficient copy)
ZZ (two deficient copies)
NULL (two non-functional copies)

The S, Z and Null genes are the ones that most commonly cause alpha-1 deficiencies and ZZ is the most common allele that causes lung disease.

Effect on the Lungs

The protein would normally circulate in the blood and help to protect the lungs from many types of damage. However the abnormal alpha-1 protein is trapped in the liver and thus causes the deficiency. The result may be emphysema (which is a condition of destruction of supporting structures/air sacs within the lung). Despite treatments adults may require a lung transplant due to severe emphysema.

Effects on the Liver

The accumulation of the abnormal alpha-1 protein within the liver cells may cause disorders such as abnormal liver function tests (without symptoms) to severe, scarring (cirrhosis of the liver) and rarely, liver cancer.

What are my chances of having Alpha-1?

"Since Alpha-1 Antitrypsin Deficiency is an inherited disorder, it occurs when both parents pass on an abnormal gene to their child. A father and mother who are both carriers (MZ) could expect to have a 50% chance of having a carrier, and a 25% chance of having either a healthy or a deficient child. With the birth of each child, the same percentages apply. Therefore, it is entirely possible for a MZ father and a MZ mother to have four children, all of which are ZZ or all of which are MM. Or on the other hand, it is possible for this same father and mother to have 1 ZZ child, 2 MZ child and 2 MM child as the percentages imply. If one parent has the ZZ genotype, and the other has two normal copies of the gene (MM), all of their children will have the MZ genotype." (Alpha-1 association)

The World Health Organization (WHO), American Thoracic Society (ATS), and the European Respiratory Society (ERS) recommend that all individuals with COPD be tested for Alpha-1.

You have been diagnosed, what now?

- First of all if you are a current smoker, then you must stop now! This is the most important factor that can improve the chance of survival. Cigarette smoke renders that available alpha-1 antitrypsin useless.
- Protect your lungs and avoid any irritants such as chemicals, pollution and dust. Choose a vocation that does not excessively expose yourself to these. Ensure that you always use/wear protective equipment (eg. Masks) if you are in environments where irritants are unavoidable.
- Seek medical advice and early treatment of respiratory infections and have annual flu vaccine and the pneumonia vaccine.
- Also take care of the liver, drink alcohol rarely if at all.
- Regular exercise, a balanced diet and generally taking care of oneself is crucial in maintaining a good quality of life if you have Alpha-1.
- Use inhaler medications as prescribed and correctly – for advice on correct technique contact Asthma Auckland for an education session with an educator.

Page 22 – Simon tells us of his experience with being diagnosed with Alpha-1 Antitrypsin Deficiency.

References:
The Selective Advantage of 1-Antitrypsin Deficiency – Prof. David A. Lomas
Alpha-1 Association: http://www.alpha1.org
What is Alpha-1 Antitrypsin Deficiency? National Genome Research Institute web site 2007 Feb <http://www.genome.gov/19518992>

Simon vs The Vikings

Tenth century Vikings have a lot to answer for, even a good thousand years on. Given their long winter nights, and limited gene pool, it was perhaps inevitable that some inbreeding was going to occur, probably with less than desirable consequences.

In this case, a mutation to the Alpha-1 gene on Chromosome 14 of our DNA has given rise to Alpha-1 Antitrypsin Deficiency in that population. The predilection of the Vikings to spend their summers spreading their genetic legacy to anyone and everyone within raiding distance of the North Sea has meant this particular mutation has become very widespread in Western Europe, and today, much further afield.

Given both sides of my family hail from this general area, it is perhaps not surprising that A1AD should crop up somewhere along the way. I have inherited a Z gene from each of my parents, and although there from conception, it took 35 years before I was finally diagnosed. This is a not uncommon occurrence, and in fact A1AD is known as one of the most prevalent but poorly diagnosed genetic conditions around.

In my case, after suffering an increasing number of chest infections in the late 1990s, my then GP decided to send me to see a Respiratory Specialist, who ordered a blood test to determine whether his suspicion of A1AD was on the mark. Unfortunately I came back as a ZZ genotype, and subsequent lung function tests showed my FEV1 levels were even at that point, down to some 32% of predicted, indicating that the resultant lung disease was already quite advanced.

Subsequent tests have also shown my liver to be affected as well, which is less common, but interesting to me, in that at age 6 weeks, I was hospitalised for several weeks with severe Jaundice. I was regarded as being lucky to have survived this, and I have to wonder if this was directly related to A1AD as well.

Liver damage was confirmed after a biopsy about four years ago, but hasn't really affected me to any degree, as it is relatively mild in comparison with the damage to my lungs, and I have made a conscious decision to continue to enjoy my red wine, as my focus is very much on quality of life rather than quantity.

I have looked very closely at options around lung transplantation, have been assessed for a transplant, and spent several years on the inactive waiting list, before a number of factors, both medical and psychological, made me realise it was not the right solution for me.

In the ten years since my initial diagnosis, I have seen a continued decline in my lung function, mainly due to an ongoing series of chest infections, and I'm now dealing with the end-stage of the disease, and the reality of only having a short time left in which to continue to enjoy life.

It has been a very interesting journey so far, and although I'm not too happy with the prospect of not making it beyond 45, there have been a huge number of positive experiences resulting from this, which have arguably made me into a better and stronger person than I likely would have been without these challenges.

At the heart of everything, the people in my life are what matter the most, and I feel very privileged that I have a hugely supportive group, both my immediate family, and the wider collection of in-laws, out-laws, friends and everyone else who continue to be there for us along the way.

These relationships, and the knowledge of what I have achieved with my life to date, have made it a lot easier to get to this point with very few regrets, and with my sense of humour still intact.

Remember – "Always Look on the Bright Side of Life" *M. Python*.

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newstream

Inhaled corticosteroid therapy for patients with persistent asthma: Learnings from studies of inhaled budesonide.

Chipps BE.
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Inhaled corticosteroids (ICSs) are recommended for patients with asthma who use a short-acting beta(2)-adrenergic agonist more than twice weekly-a key indicator of disease persistency. Much knowledge about the long-term benefits of ICSs in persistent asthma stems from studies of the ICS budesonide, which have shaped current asthma guidelines. Results of the 3-year double-blind phase of the inhaled Steroid Treatment As Regular Therapy study indicated that early ICS treatment improves impairment and reduces future risk of severe exacerbations by 44% in adults and children with ICS-naive, recent-onset persistent asthma. These benefits were maintained or improved during the 2-year open-label phase; however, the benefit of very early versus later introduction of ICS treatment on pulmonary function could not be established. Similarly, in the Childhood Asthma Management Program (CAMP) study, ICS treatment did not alter the progression of asthma. The CAMP study, however, highlighted the need for continued daily ICS treatment, thus providing evidence for the new asthma guidelines' focus on improving asthma control versus altering natural history. In patients not controlled on daily ICSs alone, the Oxis and Pulmicort Turbuhaler in the Management of Asthma (OPTIMA) and Formoterol And Corticosteroids Establishing Therapy (FACET) studies of budesonide showed benefit of ICS combination therapy with a long-acting beta(2)-adrenergic agonist (LABA). Taken together, these studies show the efficacy of daily ICS therapy in patients with mild to moderate persistent asthma, support the benefits of initiating ICSs early and continuing treatment, and underscore the need to increase to ICS/LABA in those uncontrolled on ICS alone.

Effects of the Menstrual Cycle on Lung Function Variables in Women with Asthma.

Farha S, Asosingh K, Laskowski D, Hammel J, Dweik RA, Wiedemann HP, Erzurum SC.
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RATIONALE: Angiogenesis is a defining pathologic feature of airway remodeling and contributes to asthma severity. Women experience changes in asthma control over the menstrual cycle, a time when vessels routinely form and regress under the control of angiogenic factors. One vital function modulated over the menstrual cycle in healthy women is gas transfer, and this has been related to angiogenesis and cyclic expansion of the pulmonary vascular bed. OBJECTIVES: We hypothesised that changes in gas transfer and the pulmonary vascular bed occur in asthmatic women over the menstrual cycle and are associated with worsening airflow obstruction. METHODS: Twenty three women, thirteen asthmatics and ten healthy controls were evaluated over the menstrual cycle with weekly measures of spirometry, gas transfer, nitric oxide, hemoglobin, factors affecting hemoglobin binding affinity, and pro-angiogenic factors. Measurements and RESULTS: Airflow and lung diffusing capacity varied over the menstrual cycle with peak levels during menses that subsequently declined to nadir in early luteal phase. In contrast to healthy women, changes in lung diffusing capacity (DLCO) were associated with changes in membrane diffusing capacity and DLCO was not related to pro-angiogenic factors. DLCO was not different between the two groups, though methemoglobin and carboxyhemoglobin were higher in asthmatics than healthy women. CONCLUSION: Asthmatic women experience cyclic changes in airflow as well as gas transfer

and membrane diffusing capacity supportive of a hormonal effect on lung function.

Long-term outcomes of early childhood wheezing.

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PURPOSE OF REVIEW: To summarise the currently available data on the long-term outcome until young adulthood after early childhood wheezing. Asthma and lung function abnormalities were evaluated, with special attention to early-life risk factors. RECENT FINDINGS: In postbronchiolitis studies, 30-40% of the patients hospitalised for wheezing at less than 24 months of age have had asthma at 17-20 years of age. In the Tucson birth cohort study, the respective figure after wheezing at less than 36 months of age was 30% at 22 years of age. Relapses after many nonsymptomatic years have been common. In postbronchiolitis studies, lung function has been reduced in 31-36%, concerning also postbronchodilator measurements. Thus, the changes in airways seem to be structural, being present from infancy until adulthood, as found in the Tucson study. Parental asthma, repeated early-life wheezing and early passive smoking have been the most important early-life predictors of both adulthood asthma and lung function abnormalities. SUMMARY: Early childhood wheezing increases the risk for asthma and lung function abnormalities in young adulthood. Not only chronic childhood asthma continuing until adulthood but also asthma beginning in early adulthood seems to have its origin in early childhood.

Characteristics of patients admitted for the first time for COPD exacerbation.

Balcells E, Antó JM, Gea J, Gómez FP, Rodríguez E, Marin A, Ferrer A, de Batlle J, Farrero E, Benet M, Orozco-Levi M, Ferrer J, Agustí AG, Gáldiz JB, Belda J, Garcia-Aymerich J; PAC-COPD Study Group.
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Respiratorias (CIBERES), Recinte Hospital Joan March, Carretera Soller km 12, 07110 Bunyola, Spain.

BACKGROUND: This study describes the characteristics of a large sample of patients hospitalised for the first time for a chronic obstructive pulmonary disease (COPD) exacerbation. METHODS: All subjects first admitted for a COPD exacerbation to nine teaching Spanish hospitals during January 2004-March 2006, were eligible. COPD diagnosis was confirmed by spirometry under stability. At admission, sociodemographic data, lifestyle, previous treatment and diagnosis of respiratory disease, lung function and Charlson index of co-morbidity were collected. A comprehensive assessment, including dyspnea, lung function, six-minute walking test, and St. George's Respiratory Questionnaire (SGRQ), was completed 3months after admission, during a clinically stable disease period. RESULTS: Three-hundred and forty-two patients (57% of the eligible) participated in the study: 93% males, mean (SD) age 68 (9) years, 42% current smokers, 50% two or more co-morbidities, 54% mild-to-moderate dyspnea, post-bronchodilator FEV(1) 52 (16)% of predicted (54% mild-to-moderate COPD in ATS/ERS stages), 6-min walking distance 440m, total SGRQ score 37 (18), and 36% not report respiratory disease. The absence of a previous COPD diagnosis, positive bronchodilator test, female gender, older age, higher DLco and higher BMI were independently associated with less severe COPD. CONCLUSIONS: We show that the patients admitted after presenting with their first COPD exacerbation have a wide range of severity, with a large proportion of patients in the less advanced COPD stages.

Living with chronic obstructive pulmonary disease: a survey of patients' knowledge and attitudes.

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Abstract:
INTRODUCTION: Chronic obstructive pulmonary disease ***(COPD)*** is a common respiratory condition and the fourth leading cause of death in Canada. However, little is known about the impact of ***COPD*** on the lives and attitudes of individuals living with this condition. The purpose of this study was to determine whether Canadians with ***COPD*** are properly educated and supported, and to recommend solutions to any care gaps identified. METHODS: A total of 389 Canadians were surveyed who were 40 years of age and older, physician diagnosed with ***COPD***, and current or former smokers. The telephone survey contained 68 items and took 35 min to complete. ***COPD*** severity was classified according to symptom severity using the Medical Research Council (MRC) score. RESULTS: Respondents tended to overestimate their disease severity and reported substantial symptom burden and psychosocial impact of living with COPD. Most individuals claimed to be well informed about ***COPD***; however, their knowledge was poor in several domains including the causes of ***COPD***, the consequences of inadequate therapy and the management of exacerbations. Family physicians were the main health care providers. A minority of respondents had seen a lung health educator. Only 34% had ever received a written action plan and only 33% had been told how to prevent an exacerbation. CONCLUSIONS: The symptom burden and psychosocial impact of living with ***COPD*** is substantial. There are significant gaps in patients' knowledge about the management of ***COPD*** and little contact with lung health educators. Increased use of ***COPD***-specific, self-management education programs may help rectify these care gaps.

Pulmonary rehabilitation is successful for COPD irrespective of MRC dyspnoea grade.

Evans RA; Singh SJ; Collier R; Williams JE; Morgan MD
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Abstract:
BACKGROUND: It is not clear whether the benefits of pulmonary rehabilitation (PR) apply equally to patients with Chronic Obstructive Pulmonary Disease ***(COPD)*** with different levels of starting disability. We have therefore investigated the effect of pulmonary rehabilitation stratified by the MRC dyspnoea scale in patients with ***COPD***. METHODS: This is a retrospective, observational study of data collected from 450 consecutive patients with ***COPD*** attending outpatient PR: 247 male, mean (SD) age 69.5 (8.9) yrs and FEV(1) 44.6 (19.7)% predicted. The Incremental Shuttle Walk Test (ISWT) was performed before and after the seven-week course RESULTS: 395 patients (88%) completed the programme. The mean (SD) baseline ISWT performance was 167 (113)m. The distribution of baseline MRC grades was 2 - 15.4%, 3 - 24.9%, 4 - 27.3% and 5 - 32.4%. The mean (95% CI) improvement in ISWT after PR for each MRC scale grade was highly significant (p<0.0005); 2 - 66 (50-83)m, 3 - 63 (50-75)m, 4 - 59 (49-70)m, and 5 - 54 (43-64)m. CONCLUSIONS: Patients with COPD, of all MRC dyspnoea grades, benefit comparably from pulmonary rehabilitation achieving both statistically and clinically meaningful improvements in exercise performance. MRC grade should therefore not be used to exclude patients from pulmonary rehabilitation.

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