

EDUCATING DOCTORS AND PATIENTS ABOUT ALLERGY

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Rewind back to 1991: After that pivotal British Society for Allergy and Clinical Immunology (BSACI) annual congress in London, I was hooked on Allergology! To tell the honest truth, the only reason I attended was because the Clarityne pharmaceutical representative (I think it was Rhone Poulenc Rorer in those days) offered me, as a young Cape Town GP, part-sponsorship to an overseas educational congress of my choice and the bright lights of London took my fancy. I felt obligated to at very least attend the first day's lectures and then go on my merry sight-seeing way. But I became completely transfixed by this strange new science called Allergology. I found it was impossible to leave the congress proceedings. I attended every lecture and every available workshop, absorbing all the fascinating clinical information which was completely new to me, fantastic hypotheses as to why we develop allergies, ground breaking scientific discoveries (in those days) such as "adhesion molecules" and the "eosinophilic inflammatory cascade". I studied all the posters displayed in detail and took copious notes. I was hooked, totally addicted to Allergology.

Shortly thereafter whilst still working as a Cape Town suburban GP, I managed to secure a part-time Medical Officer post at the Red Cross Children's Hospital Allergy Clinic. There I worked for one morning a week alongside the doyens of South African Allergology at the time; Eugene Weinberg and Cas Motala both of whom I found inspirational. They encouraged me to get involved with ALLSA and specifically patient education. Shortly after this, I was co-opted onto the ALLSA Executive Committee in 1992, primarily to push forward the very important portfolio of developing Patient Education materials. Initially it was a matter of adapting and updating the existing patient education booklets. I then proposed the Patient Information Sheet Series and was entrusted with supervising the written material and arranging printing of the information sheets, booklets and brochures.

I felt very honoured to be given such an important task, and the committee offered me support and endless enthusiasm,

even though at the time I was also a reluctant Treasurer for ALLSA (accounting was never my forte). At that early stage while developing patient education, I had to painstakingly type each one of the information sheets myself (pure torture for a confirmed "one finger typist") and any mistake meant retyping the whole document all over again on an old "rollerball" typewriter. But technology soon helped, when I was loaned a "hand-me-done" Word Processor by a pharmaceutical company, and I could then actually make corrections without discarding the whole document. That was a really welcome technological advance.

In the beginning it was a matter of "write it yourself if you want to get it done". Steve Lee of Laboratory Specialities was a source of editorial inspiration (he supplied the infant ALLSA with a home and office space) and he trained me on how to effectively pester the pharmaceutical companies into advertising and covering printing costs. Fortunately in those early days, there were quite a few pharmaceutical companies in the allergy market, which was before they were all gobbled up into multinationals. All of these companies were willing to dig deep in their pockets and help out. At that point there were only a handful of local allergy publications, including that magnificent 1988 book on "Pollen and Mould Allergens in Southern Africa" which coincided with the Inaugural Meeting of ALLSA (and still one of my favourite reference books).

The "Understanding Allergies" series, driven forward by Cas Motala, needed more topics covered and I wrote and added Asthma to the series. At the same time, we worked together on a complete reference book on Asthma with the promise of "government sponsorship" from one Fred Johnston (Fred, what happened to our Asthma manuscripts?). At about this point in 1994 with enormous local collaboration, there resulted the original "ALLSA Handbook of Practical Allergy" sponsored by Janssen Pharmaceuticals.

More support and advice continued to come from Steve Lee who had amazing enthusiasm and a solution to any

impasse, with good suggestions for any crisis. There would be frequent lunchtime trips down to the printer Brevan Beasley at Edson Clyde Press to check proofs and layout. Initially there were short runs of 1000 copies of information sheets per topic but as the repertoire grew and it did grow rapidly, and we were up 5000 of each document. Laboratory Specialities' Jack Larsen often coming to the last minute financial rescue when other companies budgets had dried up and we were financially stuck and just about to abandon a print run.

Then there was my "Midlife Crisis" and a 4 year sojourn to England working as an NHS GP and Clinical Assistant in Immuno-pathology at Frimley Park Hospital near London. At this point in early 1999, my fledgling private allergy clinic was set up at the Guildford Nuffield Hospital, and I later had an honorary "consultant" post at the Royal Brompton in London working with Prof Stephen Durham before finally returning to Cape Town. I still undertake clinical work in Guildford for the NHS and a private clinic in Harley Street. I created the Surrey Allergy Clinic website in 1999 at www.allergy-clinic.co.uk which I am proud to say, preceded the monolithic Google, using a pirated version of Microsoft FrontPage and endless help from a Boehringer-Ingelheim medical representative Gary Hall. This was one of the first evidence-based allergy data websites on the World Wide Web, together at the time with the ALLSA website at www.allergysa.org which was single-handedly developed by Harris Steinman who went on to develop his Allergy Advisor and other sites.

Evidence-based advice made significant advances, I had great interest from the industry including UCB Institute for Allergy and Pharmacia, developing their allergy information booklets was great fun, writing material well into the night. On the basis of this work, I was asked to develop the BBC Online "Guide to Allergies" and won the EAACI prize for Best Lay Allergy education guide at their Naples congress in 2002. An "Allergy Guide" educational book for Dorling Kindersley in London was unfortunately shelved when Penguin took over and shut down scientific publications.

Then it was back in South Africa in 2003 and welcomed back into the ALLSA family, where I developed the ALLSA Position Statement: Allergen Skin Prick Testing in 2006 with advice from Paul Potter and Richard Lockey from the USA.

The ABC of Allergology section in our journal *Current Allergy and Clinical Immunology* was the brainchild of Eugene

Weinberg, and in 2004 he entrusted me with the series to try and keep allergy education as simple and clear as possible. Each quarter I attempted to cover different topics in a couple of well-illustrated pages. After four years, in 2008 I finally ran out of ideas and steam and was delighted to hand over the reins to Shaunagh Emanuel and Di Hawarden. They have taken the ABC series to new heights with their simple clear text and Shaunagh's superb illustrations. It is certainly now time to develop their series into a stand-alone e-book handbook (with hardcover printed books being relegated to antique shops).

But it wasn't all plain sailing. Even with our best attempts to get evidence-based allergy education underway, there were still an incredible amount of misinformation resources available to healthcare workers and the general public. On this topic, I must applaud Harris Steinman's zealous ongoing campaign to protect evidence-based Allergology, which led him to come face to face with some really nasty and threatening characters. He single-handedly saw them off and went about exposing idiotic unsubstantiated allergy practices and testing, mostly promoted without many questions from the SAMDC and Advertising Standards Association of SA (ASA) except for the odd "slap on the hand". Harris campaigned for ALLSA to produce their excellent Position Statements on the subjects of IgG and ALCAT unsubstantiated allergy tests of no proven value. One has to remind oneself that "we have failed if we allow nonsense medicine to prevail and don't act as gatekeepers for better evidence-based allergy care and service provision in Southern Africa".

Once the ALLSA database of patient and doctor education leaflets and booklets was established we soon realised the extraordinary impact that the internet, Google searches and Wikipedia would have on lay health education. As a result, all the ALLSA educational material was edited, translated and placed on the website in English, Afrikaans, Xhosa and Zulu, to be downloaded as needed by members of the public. It seems unnecessary to now further develop and duplicate patient educational material and information found elsewhere. We should rather provide good links from our website to informative peer-reviewed or authenticated data resources, and most importantly to warn against using websites of no clinical or educational value. That's why in 2010 the BBC closed down their Online Health website including my Guide to Allergies! There were just too many other medical education websites to compete with on the World Wide Web and they transferred their links to the

extensive NHS Choices website.

WHAT HAVE WE FAILED TO ACHIEVE IN THE LAST 20 YEARS?

IMMUNOTHERAPY AND SKIN PRICK TESTING

There has been absolutely no progress in registering Desensitisation Immunotherapy with the Medicines Control Council (MCC) over the last 20 years. One still has to apply for Section 21 exemption and approval for these essential disease modifying vaccines without product licences. This has to be done after every 6 months of treatment and progress reports submitted to the MCC.

As a consequence of this bureaucratic and laborious hurdle, pharmaceutical companies (and doctors) are loathe to get involved with the importation of immunotherapy products. The ALK Abello range of SLIT 1 treatments and Skin Prick testing allergens are supplied in South Africa by ImmunoSpec and thankfully an old friend (Jack Larsen of Immunospec) has taken over distribution of these products including the skin prick test range. The Stallergenes range of SLIT and SIT Immunotherapy is sporadically available, as are their range of Skin Prick Test allergens, depending on whether SA Customs allows the cold-chain to be broken or not. The importation process from Europe can take 6 weeks or longer to complete. As a result of the unreliability of the supply chain, the current Stallergenes agents in South Africa, Equity Pharma are also considering withdrawal from the market.

TESTS OF NO PROVEN DIAGNOSTIC VALUE

There has been a boom in diagnostic and therapeutic products with no proven diagnostic or clinical value. This includes so-called IgG food intolerance testing available from Dis-Chem Pharmacies nationwide at considerable expense to the individual. These IgG tests are locally marketed by Imupro and they had a national Road Show this year to drum up support from dieticians (which Harris Steinman and Mike Levin responded to in an ALLSA open letter). Talking of which, I am sure we haven't seen the last of the ALCAT test, which still pops up from time to time as a food intolerance test (although now mainly to diagnose so-called intolerances causing obesity).

FRINGE PRACTITIONERS

We also see ongoing popularity with many alternative practitioners such as Chiropractors and Homeopaths of valueless diagnostic methods such as VEGA (pseudo-electrophysiological) tests and Kinesiology (muscle strength) tests. Even Hair Analysis, Live Blood Analysis

and Stool Parasite tests have made comebacks. These so-called chemical and intolerance tests are not based on any sound scientific evidence and "diagnose" everyone with intolerances to basic essential foods such as dairy, wheat, gluten, yeast and sugar, resulting in unnecessary hardship when eliminated from the diet, a practise which risks inducing malnutrition.

"Evidence based medicine" goes out the window when Patrick Holford (a very convincing journalist) arrives in town and goes on his annual South African Road Show (mainly to schools and golf clubs) promoting his unsubstantiated theories including "Hidden Allergies" book and such like, promoting IgG testing and suggesting that vitamins can be the cure for allergies.

One more additional thorn in the side of conventional Allergology and peculiar to South Africa is the Allergostop treatment which has no science behind it, but purports to cure allergies by re-injecting the person's harvested serum. This treatment should be avoided until evidence regarding efficacy can be supplied by the agents (Response by ALLSA Excom 2014).

DIAGNOSTIC PROGRESS

On the bright side, we have access to some magnificent new diagnostic tests. Most notable are the new component derived allergen specific IgE tests, including ISAC component allergen profiling which help clarify severity and persistence of allergies.

Finally, I would like to thank three committed people who made a huge contribution in the early years of developing local Allergology educational services, and who worked tirelessly to promote the Allergy Society and the development of Allergology at grass roots level. I would like to thank Cas Motala, Harris Steinman and Steve Lee for all they have done for doctor, dietician, nurse and patient education in Southern Africa.

DECLARATION OF CONFLICT OF INTEREST

The authors declare no conflict of interest.

RESOURCES ON THE INTERNET

1. ALLSA website patient information sheets http://www.allergysa.org/C_InfoBrochure.asp Last accessed 13/10/2014
2. ALLSA Position Statement: Allergen Skin-Prick Testing <http://www.allergysa.org> Last accessed 13/10/2014
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4. CAMcheck by Harris Steinman <http://www.camcheck.co.za> Last accessed 13/10/2014
5. Wikipedia Allergies <http://www.en.m.wikipedia.org> Last accessed 13/10/2014
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