Taking the long view

Patient and consumer allergy advocacy over thirty years

Hazel Gowland PhD, PGCE, MREHIS, FIFST, FRSPH

December 2023
Autumn 1993

1992
Suraj
David
Josephine
Kerry

1993
Michaela
Antoinette
Gillian
Robert
Rachel
Louise
George
Lee
Sarah
Spring 1994

The Anaphylaxis Campaign’s principal objectives are crystal clear: it wants to prevent deaths from food-induced anaphylaxis, and it wants to improve the quality of life for those who are at risk from food-induced anaphylactic shock.

Medical research is essential if we are ever to find a long-term solution to the problem. Accurate food labelling is crucial. And dramatically increased levels of awareness are vital, if the terrible risks faced daily by thousands of sufferers are to be reduced.

In the meantime, we hope you will find a great deal of support in the knowledge that you are not alone - and that something can be done to protect you and your family from the effects of this capricious and frightening condition.

- Prevent deaths
- Improve quality of life
- Research
- Accurate food labelling
- Support
- You are not alone
- Something is being done to protect you and your family
<table>
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<tr>
<th>Spring 1994</th>
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<tr>
<td>Discussions with Nicholas Soames MP, Food Minister and officials at MAFF</td>
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<td>Anaphylaxis &amp; treatment defined by expert doctors</td>
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<td>Adrenaline (auto-injectors and inhalers)</td>
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<td>Fundraising and thanks for donations</td>
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<td>Member data Contacts Which allergies? Issues they face</td>
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<td>BSACI list of allergy clinics</td>
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<td>MAFF research vegetable oil and 25% rule</td>
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<td>Chief Medical Officer letter to GPs</td>
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<td>House of Commons adjournment debate</td>
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<td>Sir Cranley Onslow MP joins AC Board</td>
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<td>Cadbury warning about peanut traces</td>
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<td>Arachis oil alert</td>
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<td>Call for data – ‘near misses’ unlabelled allergens</td>
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<td>Sesame allergy contact</td>
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<td>EU Labelling Directive - lobbying</td>
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<td>Regional reports eg ambulance times in Scotland</td>
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<td>Allergens in personal care products</td>
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<td>Allergy in schools</td>
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<td>Research – peanut allergens milk, egg</td>
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<td>Possible allergy vaccine</td>
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<td>Contact details for 22 regional coordinators covering UK</td>
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</tbody>
</table>
Nicholas Soames MP, Food Minister and MAFF

Research
- Peanut allergens
- Milk and egg allergy prevalence and impact
- Refined vegetable oils
- ‘Near misses’
- EU Labelling Directive
- Clinical studies

Policy
- Priority allergens
- EU Labelling Directive Prepacked
- Catering

Campaigns
- Be Allergy Aware
"This meeting urges Her Majesty's Government to ensure that food is labelled with all the contents stated to avoid the hazards of a fatal allergic reaction from hidden ingredients."

4th April 1995
1997 – Allergen testing

“Food in the News”
2 October 1997 9.00am - 5.00pm

Peter Beazalgette, Managing Director of Bazal Productions Ltd, and IFR Media Fellow, will give a talk “Don’t Blame Food” at 11.30am

RSVP by 15th September 1997
IFR Norwich Laboratory, Norwich Research Park, Colney, Norwich NR4 7UA, UK

Test to fight peanut deaths

A TESTING kit which detects peanut protein in foods could save thousands of people from potentially fatal allergic reactions.

Last year, three people died as a result of the allergy and many others suffered serious adverse reactions. But until now there has been no thorough way of identifying small quantities of the nut in foods.

The new test was devised at the Institute of Food Research in Norwich, aided by biochemist Dr Clare Mills. It is manufactured by Corics

Innovation: Dr Clare Mills

Diagnostics of Deaside, and can detect peanut or peanut oil in minute quantities.

The kit consists of a series of tiny walls and a detector solution which contains antibodies.

These single out peanut protein and bond it to an enzyme that causes a colour change if the nut is present.

The allergy affects one in 80 children under five, according to the Asthma and Allergy Research Centre at St Mary’s Hospital in Paddington.

According to Dr Mike Morgan, head of biochemistry at the Institute of Food Research, most deaths occur when sufferers consume food they believe to be peanut-free. This is because products not listing the nut as an ingredient can contain traces or may be contaminated in production.

“The levels of peanut required to cause an allergic reaction can be extremely small and young children can be particularly at risk,” he says.

FOR further information, contact the Institute of Food Research, tel: 01603 253323.

ANASTASIA STEPHENS

DAILY MAIL 6th August 1996
Anaphylaxis Campaign HQ from 2000
Allergy Care - An Investment for Life?

Patient status: History of Allergy/Reaction

- GP
  - Seen in surgery (by nurse)
  - Mediocre Nurse
  - Good nurse: Trained in allergy, Experienced and

- Sent away
  - "Not sure why?"
  - "To wait and see"
  - Told "no clinic"
  - "Test yourself"
  - "Allergy clinics have been disbanded"
  - "Adrenaline will cause you more problems"

- Referred (more than 2 years wait in Scotland)
  - To BSACI Clinic

- To non BSACI Clinic
- Pot Luck

- Patient status: unsure / incompetent / frightened / confused?

- Joint Consultants: (Allergist + Immunologist)
  - Consultant Allergist
  - Consultant Immunologist
  - Consultant Dermatologist
  - ENT Consultant
  - Chest Consultant
  - + Dietician / Specialist nurse
  - + Dietician / Specialist nurse

- To Specialist Nut Allergy Clinic
- To Community Nurse (specialist?)
- To any hospital paediatric department
  - Fully trained in allergy
  - Part trained in allergy
  - Untrained in allergy

- Skin / RAST testing (+ Safe challenges)
- Dietary / lifestyle advice
  - Allergen avoidance
  - Emergency protocol
  - School Support

- Dietary / lifestyle advice
- Joint Consultants

TARGETS: "Down-regulation of inflammation, relief of symptoms, avoidance of exacerbation and maintenance of quality of life."

© Hazel Gowland 2001

Mapping care pathways for allergic disease
2001 ‘May contain’
'May Contain' Labelling – The Consumer’s Perspective

HM PRISONS SECURE UNIT FOR THE CRIMINALLY INSANE

DANGER! MAY CONTAIN NUTS

THAT’S JUST THE SORT OF UNHELPFUL LABELLING THAT THE FSA IS UNHAPPY ABOUT!

Be Allergy Aware
HAVE YOU REMEMBERED YOUR OTHER GLASSES?
2003 Action Plan

![Action Plan Diagram](image-url)
# Projects of 1 Results

<table>
<thead>
<tr>
<th>Title</th>
<th>Project Acronym</th>
<th>Project Reference</th>
<th>Programme Acronym</th>
<th>Country</th>
<th>Status</th>
<th>RCN</th>
<th>Relevance</th>
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<tbody>
<tr>
<td>The prevalence, cost and basis of food allergy across Europe</td>
<td>EUROPREVALL</td>
<td>514000</td>
<td>FP6-FOOD</td>
<td>UNITED KINGDOM</td>
<td>Completed</td>
<td>75726</td>
<td>100</td>
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Emergency treatment

Important notice for users of MediHaler-mpi 400 Dose Pressurised Inhaler

3M Health Care Limited is recalling and discontinuing the product MediHaler-mpi 400 dose pressurised inhaler. This product is used as part of the treatment for allergic reactions to drugs or insect stings. This product has been manufactured since 1998. The product met specification at the time of manufacture but due to recently introduced higher standards of routine stability testing, 3M Health Care can no longer guarantee the required quality of this product throughout its shelf life.

ONLY MEDIHALER-mpi INHALERS ARE AFFECTED BY THIS RECALL. No other 3M Health Care inhalers are affected.

What You Should Do

If you have a MediHaler-mpi 400 dose pressurised inhaler, you should discuss alternative treatments with your doctor as soon as possible. Please take a copy of this notice with you. All MediHaler-mpi 400 dose inhalers should then be returned to the pharmacist or doctor who dispensed the inhaler.

3M Health Care continues to be committed to maintaining the highest standards of manufacturing quality. We are discontinuing this product in the best interests of the patient and apologise for any concern or inconvenience that this may cause.

If you have any questions you should not hesitate to ask your doctor or pharmacist.
Psychological impact, quality of life and support

Support  Vulnerable  Food  Stress  Bullying

CBT  Confidence  Counselling  Advocacy  Uninvited  Competent  Psychiatrist  Psychologist  Trust  Therapy

Excluded  Guilt  Tension  Information  Disability  Friends  Family
2006-2008 FSA guidance and local authority training
Prevention by early dietary intervention

LEAP and EAT studies
## Thresholds and severity

<table>
<thead>
<tr>
<th></th>
<th>Cow’s milk</th>
<th>Egg</th>
<th>Wheat</th>
<th>Soya</th>
<th>Peanut</th>
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<tr>
<td><strong>ED&lt;sub&gt;05&lt;/sub&gt;</strong></td>
<td>![Image of ED&lt;sub&gt;05&lt;/sub&gt; test for Cow’s milk]</td>
<td>![Image of ED&lt;sub&gt;05&lt;/sub&gt; test for Egg]</td>
<td>![Image of ED&lt;sub&gt;05&lt;/sub&gt; test for Wheat]</td>
<td>![Image of ED&lt;sub&gt;05&lt;/sub&gt; test for Soya]</td>
<td>![Image of ED&lt;sub&gt;05&lt;/sub&gt; test for Peanut]</td>
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<td>![Image of ED&lt;sub&gt;01&lt;/sub&gt; test for Peanut]</td>
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Awareness and fundraising
Allergic reaction record
How you can help the Anaphylaxis Campaign and aid research into allergies

This form has been designed to help the Campaign gain a fuller understanding about allergic reactions, what causes them, and what is the best treatment. Information we gather will be made available to doctors and scientists working in allergy research. If you, or a family member, has an allergic reaction to a food or substance, however minor, would you please fill in the form as soon as possible after the reaction has occurred - and after the patient has recovered - and send it to: Anaphylaxis Campaign, PO Box 275, Farnborough, Hants GU14 6SX.

UK Fatal Anaphylaxis Registry

THE CORONERS’ SOCIETY OF ENGLAND & WALES
Measuring skin to muscle distance with ultrasound

More people contacted the Campaign by email in 2016

2015
Social Media
Email
Calls

2016
Social Media
Email
Calls
2003 – 2023

MANAGING EMERGENCIES

EDUCATION

CONSUMERS

LINKING RESEARCH WITH REAL LIFE

Resuscitation Council UK

NHS Department of Health & Social Care

National Allergy Strategy Group

WAO WORLD ALLERGY ORGANIZATION

Royal College of Emergency Medicine

The Association of UK Dietitians

BDA

Royal College of Physicians

EAACI

RCPCH Royal College of Paediatrics and Child Health

Leading the way in Children’s Health

THE CORONERS’ SOCIETY OF ENGLAND & WALES

BSACI Improving Allergy Care through education, training and research

Royal College of Nursing

The voice of nursing.

College of Paramedics
Taking the long view

- Access to allergy care and safe interventions
- Information provision especially in catering
- Innovation to reduce risks – information, treatment
- ‘Near miss’ and fatal investigations and lessons learned
- New and emerging allergens
- The impact of climate change and food supply
- Regulating Precautionary Allergen Labelling – practical, possible, acceptable?