

# The Importance of a Strong National Association

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# Background

## Why the Clinical Care of Those with CF is so Important



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# Why the Clinical Care of Those with CF is so Important

CF is a genetic condition that arises when the body's mechanism for controlling mucus is faulty.

Healthy, essential mucus is thin, lubricating and anti-bacterial. It enables vital organs to work properly.

The mucus which is produced by those with CF is the exact opposite.

It is thick, congealing and attracts infections by providing an ideal environment in which they can thrive.

In other words, the mucus becomes an enemy rather than a friend.



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# Why the Clinical Care of Those with CF is so Important

Although other organs are also affected, the two where the problems arising are most severe are the lungs and the digestive system.

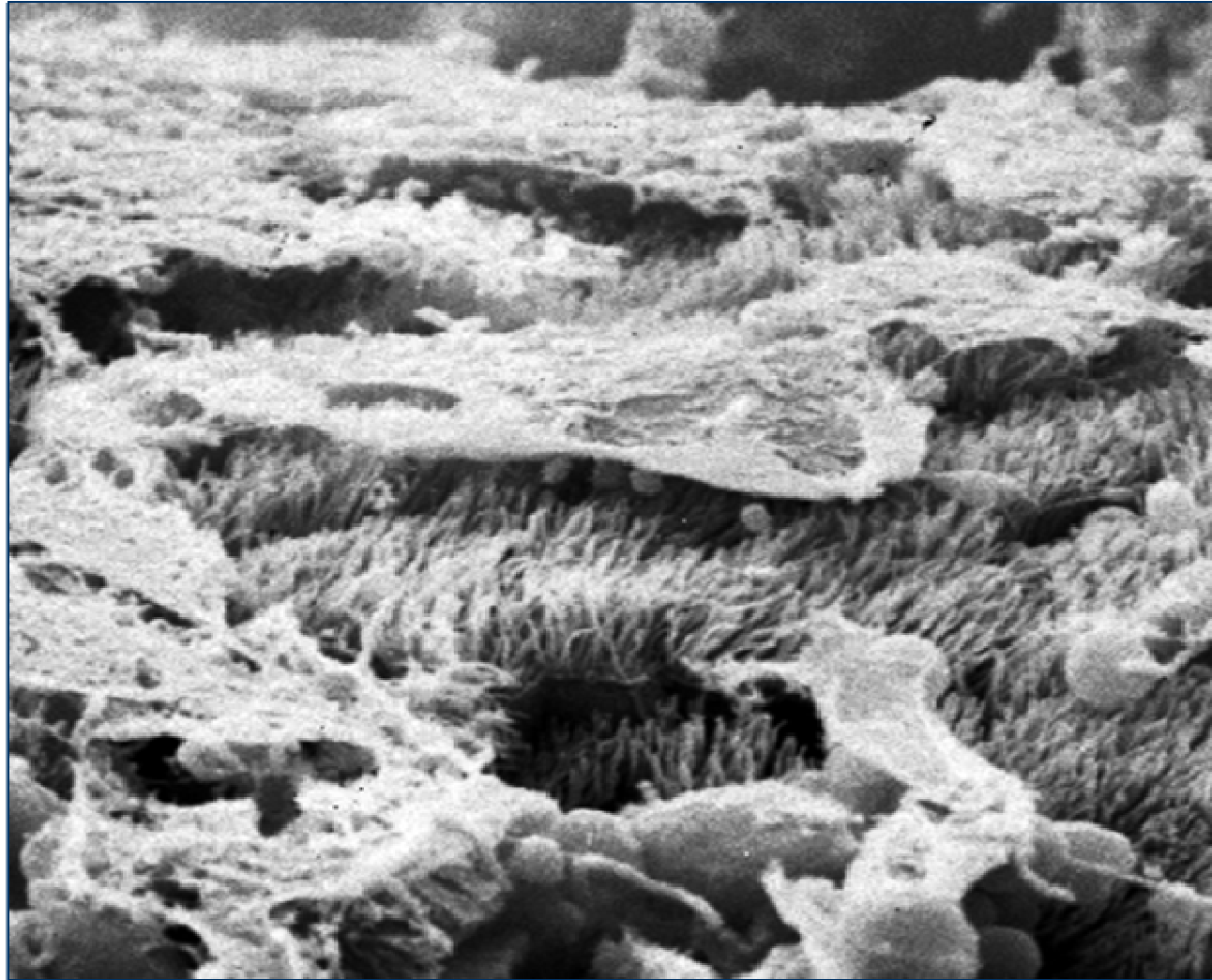
In days gone by in the UK, many babies and young children died as a result of being 'unable to thrive'. In other words, as they could not absorb essential nutrients from their food, they were so badly nourished that they died.

Now, as the digestive problems are much better controlled with the use of enzymes, the main problem is the respiratory system as the lungs become congested, infected and damaged.



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# Mucus on the lung



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# Healthy Lungs



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# CF Lungs



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# Why the Clinical Care of Those with CF is so Important

Now in the UK 90% of deaths from CF are due to lung disease.

BUT the average life expectancy is now nearly 40 years of age and improving year on year.

How has this been achieved?





# Families

If appropriately informed, families can make a huge difference, especially by ensuring healthy eating for CF – high calories and lots of fat! and by doing physiotherapy\* effectively and regularly.

\*Including plenty of natural activities – swimming, playing football, playing musical instruments which involve blowing.



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# Families

With regular, intensive medical care and intervention, right from birth.

Vital ingredients include:

- Newborn screening.
- Specialist teams in identified hospitals.
- Specialist doctors, nurses\*, physiotherapists\*, dietitians\* and social workers.  
\*The importance of these roles cannot be overestimated.
- Appropriate medication focusing on the daily use of large quantities of enzymes with every meal or snack (Creon) and antibiotics – oral, nebulised and intravenous.
- Compliant families and individuals (easier said than done, especially with teenagers).
- Only possible if appropriate medication and equipment is available and affordable.



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# What a national organisation can do

Having a focused, national organisation has been extremely helpful, if not essential, in achieving this progress.

A national organisation can:

- Agree standards of care
  - the ideal
  - what is possible now
  - A timetable for improvement.
- Have a national database
  - How many patients
  - Where they are
  - How they are doing

STATISTICS AND INTERNATIONAL COMPARISONS CAN  
BE POWERFUL.



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# What a national organisation can do

- Be a recognised focal point for discussions between
  - the government
  - the hospitals
  - the medical teams
  - the families
- Support families
  - Emotionally
  - By providing information
  - With welfare grants



# What a national organisation can do

- Liaise with medical teams
  - In a constructive but determined manner  
CONFRONTATION RARELY ACHIEVES LONG TERM, SUSTAINABLE IMPROVEMENTS – and CF is a long term condition.
- Liaise with local hospital authorities.
- Liaise with local government.
- Liaise with national government.

# But...

Rome wasn't built in a day!

- Cultural difficulties
- Financial difficulties
- Personal difficulties

So – slow, steady progress on

- What can be achieved
- What is possible now

With a plan for steady expansion of role as becomes appropriate and possible.



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# How to start?

- Small steps
- Consistent
- Repeatable
- Gradually increasing, gaining recognition, by families, medical professionals and authorities.

## Need:

- Someone who has the time
- Who is friendly, well liked, but focused.
- Keep it impersonal
- Make it professional





# Have one first agreed objective

Eg, dietetic input

- Well nourished children do much better and a CF trained dietitian can make a real difference.



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