

# The Role of a National Charity or NGO

One Authoritative voice

Able to inform:

Families and patients

AND

Doctors, Nurses, Physiotherapists, Dieticians,  
Psychologists, Social Workers & Geneticists

AND

The Federal Government, Ministry of Health,  
Regional authorities, Schools, Universities,  
Employers



# Only ONE NATIONAL AUTHORITATIVE VOICE

**Despite the size of Russia and noting the number of those with CF.**

**Two or more organisations can lead to: -**

- ❖ A divided opinion, which leads to no action
- ❖ Competition for funds and support
- ❖ Rivalry causes confusion
- ❖ Diverts energies into two or more channels
- ❖ People and organisations do not know which organisation to turn to or to believe.





Кто виноват из них, кто прав - судить не нам;  
Да только воз и ныне там.



# The importance of objectives (1).

- ❖ Clear and relevant
- ❖ Achievable
- ❖ Focused
- ❖ Short term – most vital, crucial
  - “low-hanging fruit”
- ❖ Long term – **less likelihood of early success**
  - less important
  - less affordable



# The importance of objectives (2).

- ❖ **They must be important for families and should make a noticeable impact on their daily lives.**



# Governance – The importance of the Board's composition

- ❖ Patient focused
- ❖ Families heavily involved
- ❖ Patients themselves with stringent cross infection controls
- ❖ Clinicians – Doctors, nurses, physiotherapists, dieticians
- ❖ Scientists and researchers
- ❖ Social workers
- ❖ Psychologists



# Governance – The importance of the Board's competence.

The Board oversees the charity and is accountable for its activities. Like all Boards, its members should offer certain appropriate skills:

**An ability to make a contribution to the improvement of CF healthcare and including medical professionals, scientists and those with business and management skills**

And for example relevant experience in :

**Financial/ accounting**

**Legal issues**

**Fundraising**



# Patrons?



**Influential**

**Ultra helpful .....**





# Patient focused ..... so

## Patient Advisors in UK (All have CF).

- 8-10 Regional representatives
- Never meet face to face
- Communicate via teleconference, video conference, social media such as Facebook
- The voice of patients in their area to inform local decision-making
- Inform regional and national bodies
- Influence but not direct national policy



# CF Scientific Research

Important to inform and direct research projects.

National body determines and agrees research priorities.

All research commissioned should be subject to strict peer review.

Use National and International reviewers of high repute.

**Note.** Improved clinical care is usually the first priority and research may be one of the longer term objectives.



## Общероссийская общественная организация

- Is it a patient support organisation?
- Or a Doctors' or medical professionals' Forum?
- Or does it exist to promote research?
- Or, maybe, a combination of all 3?



# A possible starting point

**A reliable source of information and support for all of those affected by CF, including families and the medical profession**

**A vehicle to influence and obtain a high standard of appropriate clinical care for all CF patients**



# What do those affected personally by CF need?

## Communication –

Someone to talk to – telephone help line

Authoritative advice – “Ask the expert”

## Proper medical care –

Good clinical care as an in-patient, an out-patient  
AND at home.

Free or affordable care

**HOPE = НАДЕЖДА**



# CF care is costly. How can the State help?

Access to free prescriptions and equipment

or adequate benefits to cover all or most of the costs for families and patients .....

in hospital

as an out-patient and

at home



## Tools for clinical care (1)

1. Nationally agreed Standard to which patients are entitled.
2. Specialist doctors and other clinicians, who are experienced in CF.
3. National clinical database or register. This enables monitoring of patients, compliance with the national Standard and can be used to manage funding of CF centres.



## Tools for clinical care (2)

### 4. Peer review of clinics to aspire to excellence.

Much of the above is dependent on the Charity («OOO») being recognised, acknowledged and respected as an organisation





# Raising funds

From and by families , eg sponsored runs, hand car washes

Charitable Trusts – eg Bill Gates Foundation

Wealthy benefactors

Pharmaceutical companies

Businesses and banks



# Ideas for using funds (1)

1. Authoritative and family friendly booklets/ leaflets (**notwithstanding internet access**).
2. Appropriate Standard document for doctors and other clinicians.
3. A comprehensive website, encompassing the above.



# Ideas for using funds (2)

4. Grants of money for families and patients to help with:
  - Medication
  - Equipment
  - household adaptations
  - holidays
  - adult start-up grant
  - funerals



# More ideas for using funds – investing in clinical care

- Paying the salaries of doctors and other clinicians
- Paying for students – “apprenticeships” into CF
- Investing in hospital facilities – wards, adaptations, outpatient rooms

Difficult decisions requiring clear thinking!



# What costs less is

Lobbying, informing, discussing .....

Pressurising those in a position to improve matters .....  
To do so.



# The ultimate choice

❖ Option 1. Achieve good publicity, to shame, to embarrass but with little to show for it in outcomes

**OR**

❖ Option 2. Be practical, constructive and persuasive to achieve real results.



**Спасибо за Ваше внимание**



**Thank you for your attention!**

[www.cftrust.org.uk](http://www.cftrust.org.uk)

[www.childhealthinternational.org](http://www.childhealthinternational.org)

