

*European Conference on Polio,  
Copenhagen, September 2nd, 2011*

**Awareness of post polio syndrome in  
the political and social system:  
COST-EFFECTIVENESS**

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# Why economic considerations?

**”Money makes the world go around”**



**Money is a metric people think they know**

**Money is also equal to resources**

**Money catches the attention of political decision makers**

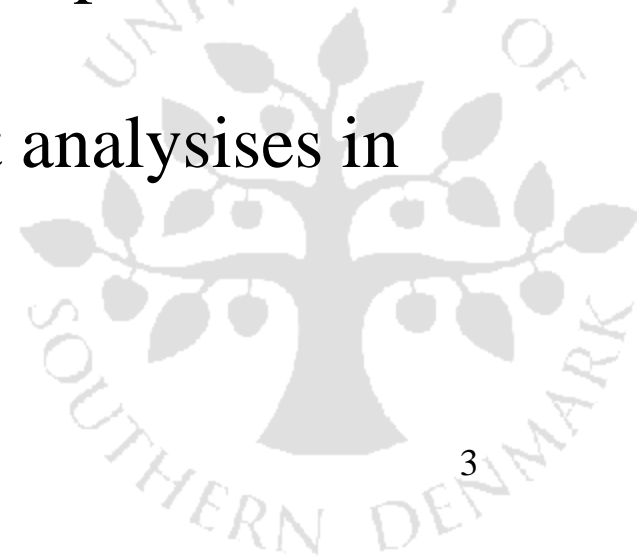


# The issue

Post-Polio Syndrome patients experience many types of illness-related problems and need special support from both social and health-care services including medical, rehabilitative, educational and social work services.

Health and social authorities are thus tasked with providing these interdisciplinary services and appropriate resources.

Can health economics provide relevant analyses in this regard?



# Health economists ...

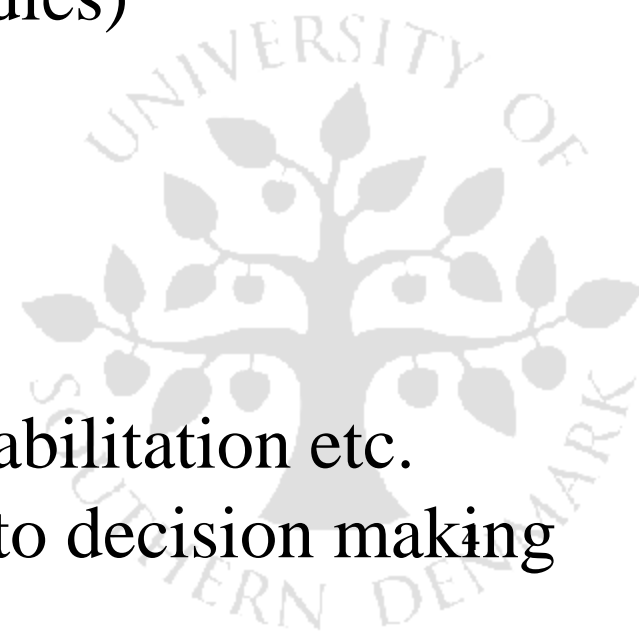
## Two types of analyses

1. Look at the economics consequences of disease

- **the economic burden** of, for instance polio or post-polio syndrome (also known as cost-of-illness studies)

2. Look at the relationship between health gains and associated costs

- **cost-effectiveness** of treatments, prevention, health promotion, rehabilitation etc.
- increasingly popular as an aid to decision making



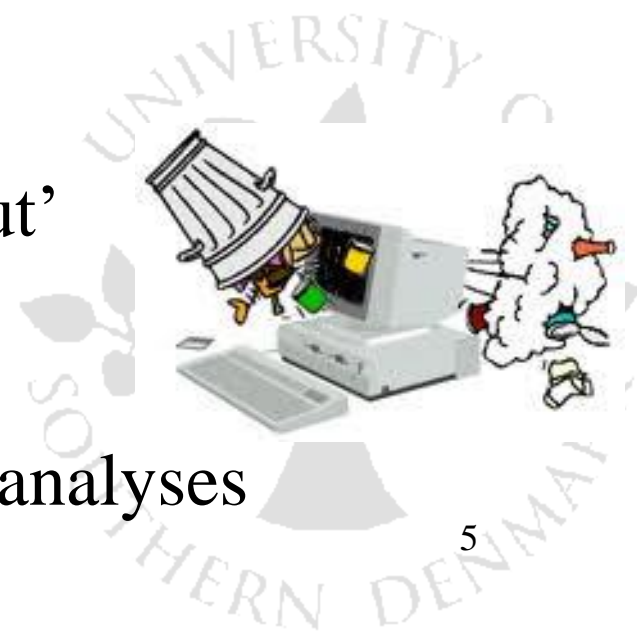
# However ...

**We need data about at least**

- **prevalence and/or incidence of PPS**
- **(expected) treatment effects (health benefits)**
- **expected costs and savings**
- **labor market consequences**

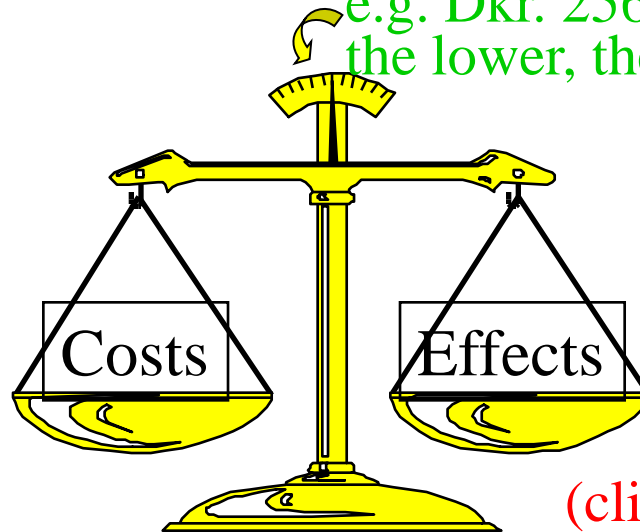
And 'if garbage in – then garbage out'  
Good data is a sine qua non.

Or even worse: No reliable data, no analyses



# Cost-effectiveness og cost-utility analyses

Cost-effectiveness ratio,  
e.g. Dkr. 256,000 per QALY, or per pain unit  
the lower, the better



## **COSTS**

- Treatment costs (direct costs)
  - no matter who pays
  - societal perspective
- Resources saved
- (normally) not indirect costs
  - sicke leave/disability/premature death
- Ideally data (volume/quantity) collected as an integrated part of the clinical trial
- Unit costs should ideally be marginal, not
  - average costs ('charges' are of dubious value)

## **(clinical) EFFECTS**

- from clinical trial/meta analyses
- 'natural units', e.g. pain, fatigue, ADL
  - depends on clinically accepted end points
- Quality adjusted life years, QALY or DALY
  - then the analysis becomes a cost-utility analysis
  -



Contents lists available at ScienceDirect

Vaccine

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## Economic analysis of the global polio eradication initiative

Radboud J. Duintjer Tebbens<sup>a,b,\*</sup>, Mark A. Pallansch<sup>c</sup>, Stephen L. Cochi<sup>d</sup>, Steven G.F. Wassilak<sup>d</sup>, Jennifer Linkins<sup>e</sup>, Roland W. Sutter<sup>e</sup>, R. Bruce Aylward<sup>e</sup>, Kimberly M. Thompson<sup>a</sup>

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## Eradication versus control for poliomyelitis: an economic analysis



The Lancet, vol 369, 2007: 1363-71

*Kimberly M Thompson, Radboud J Duintjer Tebbens*

*Risk Analysis, Vol. 26, No. 6, 2006*

DOI: 10.1111/j.1539-6924.2006.00831.x

## Retrospective Cost-Effectiveness Analyses for Polio Vaccination in the United States

Kimberly M. Thompson<sup>1,2\*</sup> and Radboud J. Duintjer Tebbens<sup>1,3</sup>



# Main result from Retrospective Cost-Effectiveness Analyses for Polio Vaccination in the United States

The historical and future investments translate into over 1.7 billion vaccinations that prevent approximately 1.1 million cases of paralytic polio and over 160,000 deaths

Due to **treatment cost savings**, the investment implies net benefits of approximately \$180 billion (1955 net present value), even without incorporating the intangible costs of suffering and death and of averted fear.

Retrospectively, the U.S. investment in polio vaccination represents a **highly valuable, cost-saving public health program.**



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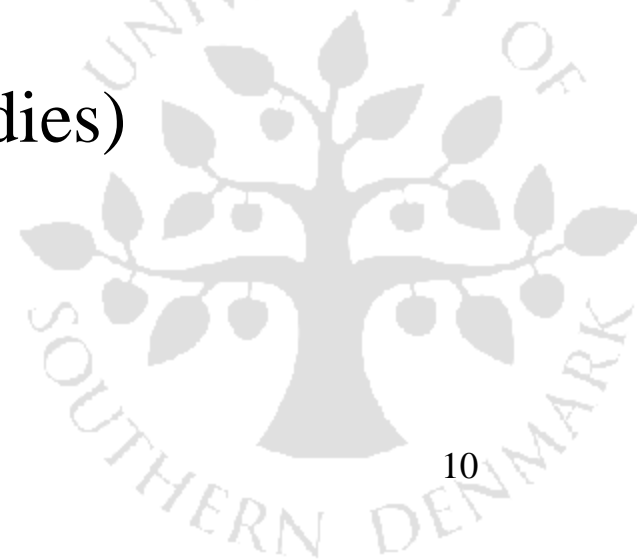
- ✓ More than 8 million cases of life-long polio paralysis prevented
- ✓ Net benefits between US\$ 40-50 billion through 2035; low-income countries account for 85% of savings
- ✓ Polio eradication is cost-effective
- ✓ Between US \$17-90 billion in additional savings from add-ons such as Vitamin A



# 'Easy' to make economic evaluation of polio vaccines ...

... because the effectiveness of the vaccine is well-known

**However**, the same cannot be said about treatment (pharmacological and non-pharmacological) of the post-polio syndrom (at least as I understand available studies)





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## **AUTHORS' CONCLUSIONS:**

Due to insufficient good quality data and lack of randomised studies **it is impossible to draw definite conclusions on the effectiveness of interventions for PPS.** Results indicate that intravenous immunoglobulin (IVIG), lamotrigine, muscle strengthening exercises and static magnetic fields **may be beneficial but need further investigation**

# Upcoming study:

Exercise therapy and cognitive behavioural therapy to improve fatigue, daily activity performance and quality of life in Postpoliomyelitis Syndrome: the protocol of the FACTS-2-PPS trial [Koopman et al. BMC Neurology 2010, 10](#)

## Economic evaluation

Cost-effectiveness and cost-utility will be evaluated from *a societal perspective*. The costs will include *direct health care costs* of visits to general practitioners, medical specialists, therapists, medications and assistive devices, direct non-health care costs i.e. non-reimbursable costs for complementary medicine and over-the counter medication, and indirect, non-health care costs of changes in paid and unpaid work. All these data will be collected via cost diaries.

...*The effect measures* used in the economic evaluation will be our primary outcome measure fatigue and HRQoL measured with the EuroQol-5D [41] at the four different time measurements. Utilities will be derived using the Dutch tariffs and used to determine qualityadjusted life years (QALYs)

# Health economists ...

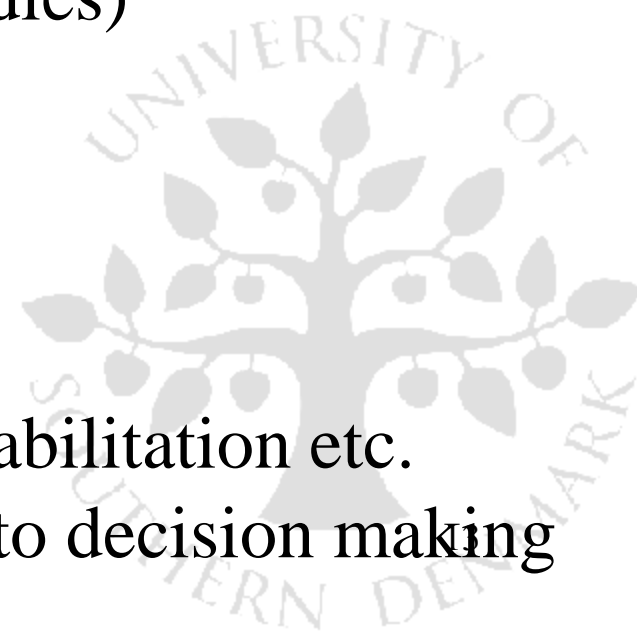
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# Economic burden PPS

Defined as the value of the resources that are expended or foregone as a result of a health problem, in casu PPS. The analysis includes health sector costs (**direct costs**), the value of lost productivity by the patient (**indirect cost**), and the cost of pain and suffering (**intangible costs**).

Number of persons with PPS, N, (prevalence)

Their use of health services, X, and family costs

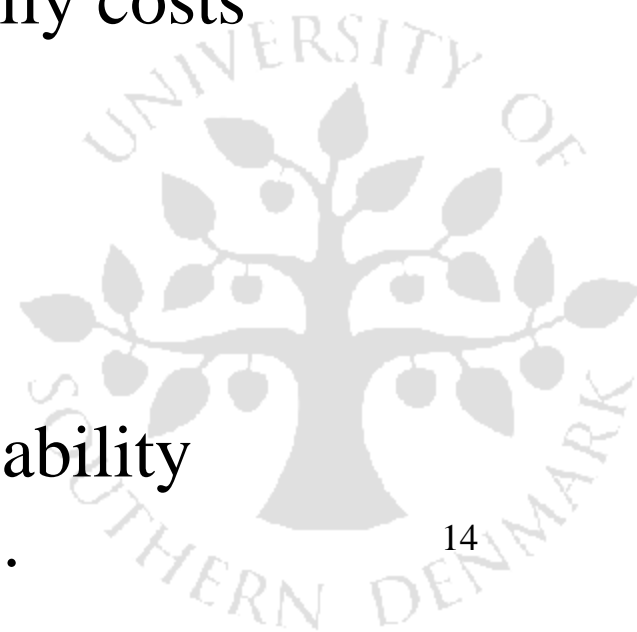
The costs of services, p

$$N * X * p$$

**PLUS labor-market consequences**

\* fraction of N with impaired working ability

\* sickness absence/disability pension ...



# No studies of economic burden of PPS

## Prevalence, N:

The prevalence of PPS has been reported from 15% to 80% of all patients with previous polio depending on the criteria applied and population studied [4,6,11,15–18]. In many population-based studies, terms like ‘late onset polio symptoms’ have been used instead of PPS. Hospital-based studies use the term PPS, but in these studies it is always debatable whether the patient material is representative. Exact prevalence of PPS is therefore difficult to establish. For European populations, one Dutch study reported a prevalence of late onset polio symptoms of 46%, one study from Edinburgh reported a prevalence of more than 60%, in Estonia a prevalence of 52% has been reported, Norway 60% and Denmark 63% [6,12,19,20].



# For the labor market consequences we need more data like:

**“Overcoming barriers to work participation for patients with postpoliomyelitis syndrome”**  
*Disability and Rehabilitation 2011, Vol. 33(6)522-529*

Work 25 (2005) 155–161  
IOS Press

## Vocational implications of post-polio syndrome

Lisa M. Elrod, Merten Jabben, Gina Oswald and Gary Michael Szirony\*  
*CARE Department, University of Arkansas at Little Rock, Little Rock, AR 72204, USA*



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## Polio - The Late Effects Reality

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### SUMMARY OF FINDINGS

The main findings of the survey are:

#### 1. Reduction in Physical mobility

Overall, most respondents have experienced some reduction in physical ability over years in a range of areas, mostly around mobility. The pace of this change does not seem to be relatively slow with most of the change occurring in from None to Mild, some change from Mild to Moderate and a very small amount of change from Moderate to Severe.

People are finding most difficulty with walking (without sitting to rest), bathing, shopping, homes, shopping and accessing the community. Bathing and mobility are the two most common issues with respect to physical assistance - aids, appliances and services.

#### 2. Population diagnosed with the Late Effects of Polio

There are 74 (34%) respondents with a clinical diagnosis. Most (48 (68%)) were diagnosed by Orla Hardiman at the Beaumont Clinic in Dublin but there was also a wide variety of other practitioners who made diagnoses. The earliest diagnosis of LEP reportedly recorded was in 1960, with the majority starting around 1990, with the bulk being in the last five years.

#### 3. Links between mobility & access to the built environment with Transport and Social Isolation.

It was established beyond all reasonable doubt that there is a definite link between reduced mobility and social isolation. This is not helped by the dearth of adapted or suitable public transport outside of Dublin and other cities, i.e. low floor buses. Benefits relating to mobility are not always available regardless of age. As one respondent said "Why don't they pay mobility people over 65? Free travel isn't much good to folk in a wheelchair, particularly if it's

## The Cost (Irish survey): Private costs

The average cost per respondent over the next 5 years of meeting all the needs **for aids and appliances** equates to some € 5,450 at 2003 prices. The Post Polio Support Group has a membership at time of writing (August 2003) of 450, so it can, therefore, be deduced that, to satisfy all their needs for mobility and aids to daily living, the members need some € 2.4m at 2003 prices.

Extrapolated across the whole of the derived LEP population in Ireland this amounts to around € 23m being needed across the next 5 years to satisfy the perceived needs.

... the amount that carers donate to the coffers through their unpaid service is  
€ 12.65m per annum.

# If we – to some extent – believe that..

**”Money makes the world go around”**



**Money is a metric people think they know**

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**We need more health economics research ...**





## COI and research

Health sector costs	Family costs
Hospitalization	Out-of-pocket payments (user fees) for hospitals and drugs
Medication	Medication
Emergency (ambulance) transportation and care	Transportation of the patient and family
Outpatient and primary clinic	Costs for taking care of dependents
	Modifications in home as a

Economists consider health to be a human capital investment. According to this approach, the value of health is measured in terms of its contribution to production activity and national income. By following the methods developed in the human capital approach, we can measure indirect costs by using data from the labor markets. Earnings lost because of time spent while ill or receiving medical treatments are used to estimate the value of time lost. Examples of indirect illness costs include the value of time spent when unable to work as productively because of an illness or side effect, earnings lost while traveling to health-care facilities, and productivity losses associated with caregiver time

# Pubmed: 'post-polio syndrome' – only 738 references

*European Journal of Neurology* 2006, **13**: 795–801

doi:10.1111/j.1468-1331.2006.01385.x

## **EFNS TASK FORCE/CME ARTICLE**

### EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force

E. Farbu<sup>a,1</sup>, N. E. Gilhus<sup>a</sup>, M. P. Barnes<sup>b</sup>, K. Borg<sup>c</sup>, M. de Visser<sup>d</sup>, A. Driessen<sup>e</sup>, R. Howard<sup>f</sup>,  
F. Nollet<sup>g</sup>, J. Opara<sup>h</sup> and E. Stalberg<sup>i</sup>





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Health Policy 71 (2005) 97–106

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## Postpolio syndrome: a challenge to the health-care system

Carmen Bouza\*, Ana Muñoz, José María Amate

validate [6]. Furthermore, the new symptoms and ensuing reduction in functional capacity generate new health-care needs and demands which at times tend to go almost unnoticed by health professionals and managers, fueling anxiety among polio survivors [8–10].

health-care level. PPS patients experience many types of illness-related problems in their everyday lives and need special supports from both social and health-care services including medical, rehabilitative, educational and social work services. Health and social authorities are thus tasked with providing these interdisciplinary measures and appropriate resources. However,



## ADDITIONAL SUMMARY OF FINDINGS *[Explanation]*

### IVIG versus placebo for postpolio syndrome

Patient or population: patients with postpolio syndrome

Settings:

Intervention: IVIG versus placebo

Outcomes	Illustrative comparative risks* (95% CI)		Relative effect (95% CI)	No of Participants (studies)	Quality of the evidence (GRADE)	Comments
	Assumed risk	Corresponding risk				
	Control	IVIG versus placebo				
<b>Change in activity limitations</b> Measured with the SF-36 PCS <sup>1</sup> . Scale from: 0 to 100. Follow-up: 3 months	The mean change in activity limitations in the control groups was <b>-0.8</b> <sup>2</sup>	The mean Change in activity limitations in the intervention groups was <b>2.3 higher</b> (0.35 lower to 4.95 higher)		135 (1 study)	⊕⊕⊕○ <b>moderate</b> <sup>3</sup>	
<b>Adverse events</b>	See comment	See comment	Not estimable	162 (2 studies)	See comment	See additional table 1

\*The basis for the **assumed risk** (e.g. the median control group risk across studies) is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).

CI: Confidence interval;

GRADE Working Group grades of evidence

**High quality:** Further research is very unlikely to change our confidence in the estimate of effect.

**Moderate quality:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

**Low quality:** Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

**Very low quality:** We are very uncertain about the estimate.

<sup>1</sup> SF-36 PCS: Short Form-36 Health Survey Physical Component Summary. Higher scores represent fewer activity limitations.

<sup>2</sup> The control group received placebo.


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- Behandling
- Gammaglobulinbehandling**
- Erfaring med gammaglobulin
- Stop for gammaglobulin
- Psykologi
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- Litteratur
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- For behandlere
- Postpolio for behandlere
- For fysioterapeuter
- For erøterapeuter

**Gammaglobulinbehandling**

Mandag, 13. oktober 2008 00:00



Under dette punkt har vi samlet artikler fra postpolio.dk om gammaglobulinbehandling af postpolioramte. Det er ikke muligt for postpolioramte at få gammaglobulinbehandling i Danmark, og der forskes ikke i behandlingen i DK. Vi vil gerne stilles lige med poliooverleverne fra Sverige, hvor behandling med gammaglobulin er et gratis tilbud til PPS ramte i Stockholms Len. Polioramte fra andre len skal først søge i eget len om at få betalt behandlingen.

Postpolio.dk har oversat mange artikler til dansk og udarbejdet et overblik i artiklen [Fakta om gammaglobulin - behandling og virkning](#). Siden 2009 har det været muligt at søge om at få behandling med gammaglobulin på Danderyd Sjukhus, Stockholm. Denne mulighed eksisterer ikke længere, men det er formodentlig stadig muligt mod egenbetaling at få behandlingen i Sverige.

Nederst findes stadig vores rejsebeskrivelser og rejsevejledning.

**Stop for gammaglobulinbehandling!!!**

1. januar 2011 blev alle lovede gammaglobulinbehandling sat i bero. D. 24. maj 2011 besluttede Region Hovedstaden at følge beslutningen fra Region Midtjylland om at færdigbehandle de postpolioramte fra ventelisten. Se oplysninger herom og følg med i sagen på forsiden af postpolio.dk: [Nyheder: Stop for gammaglobulin](#)

Behandling af danske postpolioramte i Sverige er derfor stoppet. Der bevilges ikke nye behandlinger med gammaglobulin i Danmark på sigt.

**Statistik**

Initiativgruppen har siden 2008 arbejdet på at få gammaglobulinbehandling til postpolioramte, i første omgang i Stockholm. 74 postpolioramte har været visiteret til behandling. Heraf har 27 fået behandling. Region Hovedstaden har haft 52 visiteret. Region Sjælland har haft 11 visiteret. Region Syd har haft 1 visiteret. Region Midtjylland har haft 10 visiteret.

1 har ikke kunnet tåle behandlingen. Nogle få har søgt men fået afslag i første omgang, da generne kan skyldes anden sygdom.

Enkelte har været udsat for, at der er sået tvivl om, hvorvidt de har haft polio. Det er vigtigt at få klarhed over diagnosen. Har man

