Getting the right clinical care and managing transition from paediatric to adult services

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The common problems

- Delay in diagnosis
- Finding the right specialist services
- Access to services in other cities
- Moving from Paediatric to adult services
- Adult access to Paediatric specialists
- Funding of novel therapies
- Getting disability support & equipment
- Finding palliative care when you need it

The New Zealand solutions

- Submissions to government to improve genetic services
- Advocacy for a National Metabolic service responsible for all Lysosomal patients
- Joint position statement with Paediatric Society about transition to adult care
- Joined the Access to Medicines coalition to improve medicine funding and access criteria

The New Zealand solutions

- Complaint to Health & Disability Commissioner about problems with standards of care and lack of referrals
- Advisory group to improve Paediatric services
- Newborn screening advisory committee
- Committee on assisted reproductive technology

Complaint to Health & Disability Commissioner

- The H&D Commissioner is a statutory position with investigative and reporting powers
- LDNZ gathered case studies from 14 NZ families with Lysosomal diseases
- Identified failures in appropriate assessment, service delivery, referrals, etc

HDC Code of Rights

- Right 4 - Services of appropriate standard
- Requires DHBs and health professionals to provide services that
  - Comply with relevant standards
  - Are consistent with patients' needs
  - Minimise potential harm
  - Optimise quality of life
  - Include co-operation to ensure quality and continuity of services

Our proposed solution

- All Lysosomal patients to have their health needs formally overseen by the Specialist Metabolic service, regardless of the patients' location in New Zealand, and without the need for case by case referrals from local DHBs.
- All surgery to be done at a major centre, unless specifically delegated.
- A protocol based on the transition position statement is developed to ensure appropriate and continuous care for all Lysosomal patients regardless of age.
- Nationally co-ordinated care is given to all Lysosomal patients, though some aspects of this care may be regionally provided.

Commissioner's messages

- To Director General of Health 2007
  - "I agree that the current situation is untenable and would appreciate it if the Ministry could afford priority to finding a solution…"
- To NZORD's 2009 workshop
  - "In my view there is a responsibility to make reasonable provisions for the needs of those with rare disorders, rather than leaving them to languish on priority lists…."

Ministry's response

- LDNZ proposal for specialist management of all Lysosomal patients accepted in principle in March 2008
- An important lever in current work to develop national services and managed clinical networks
- Assisted by the health policies of the new government

Conclusion

- There is much more needed than just lobbying
- Patients and families as active participants in the information, clinical care and research issues

"These examples demonstrate the changing face of support groups. They are staking claims for a role in research by providing epistemological information about their diseases, and becoming active partners in debates and practices about them."

V. Rabeharisoa et M. Callon. Histoire et Sciences Sociales, Medicines/Sciences 2000; 16: 945-9

And now for the solutions being worked on in other parts of the world

My family

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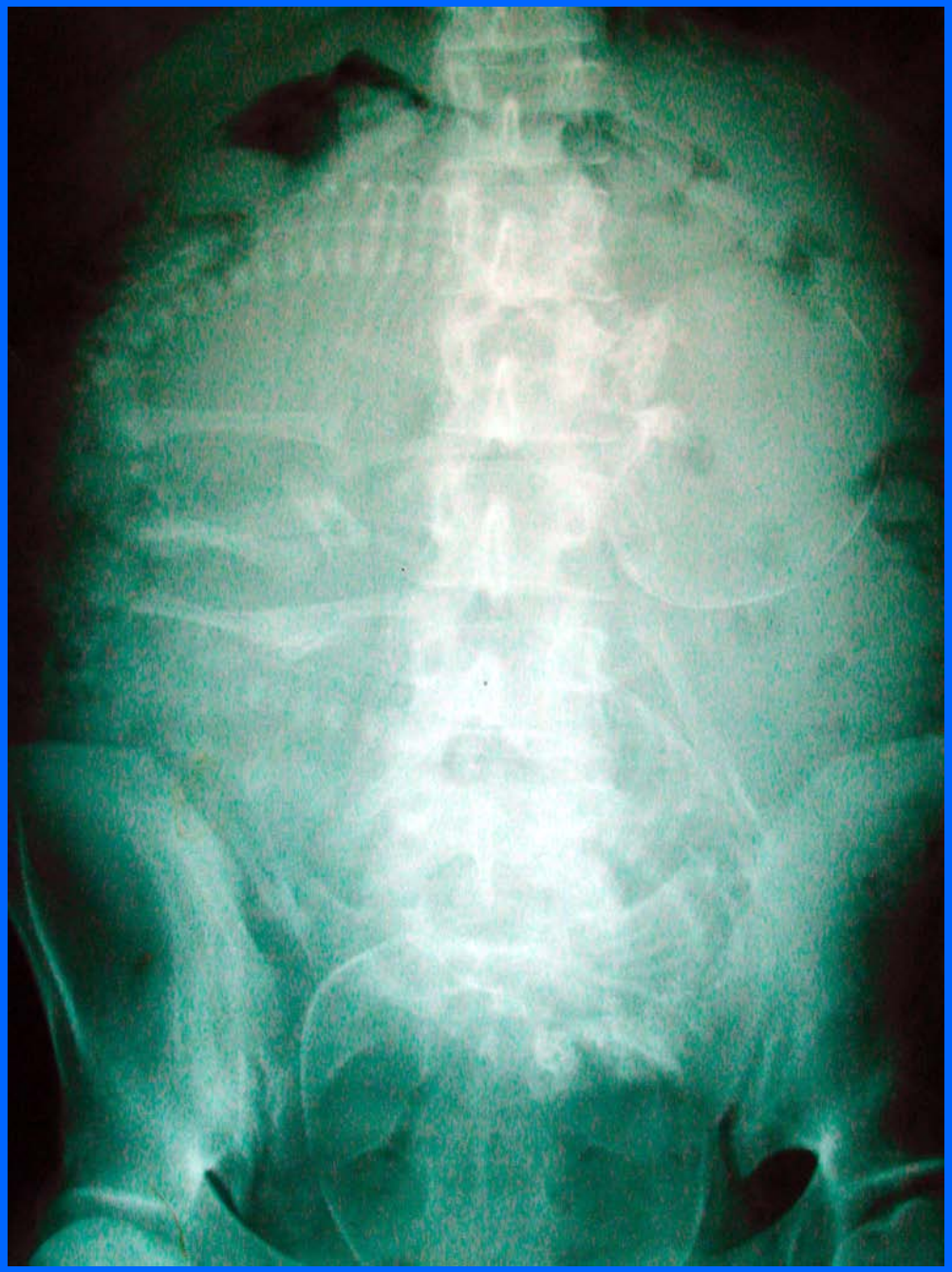

John, Judith, Timothy and Hollie