

Workshop on paediatric pulmonary arterial hypertension (PAH)

Endpoints – Patients perspective

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Presentation

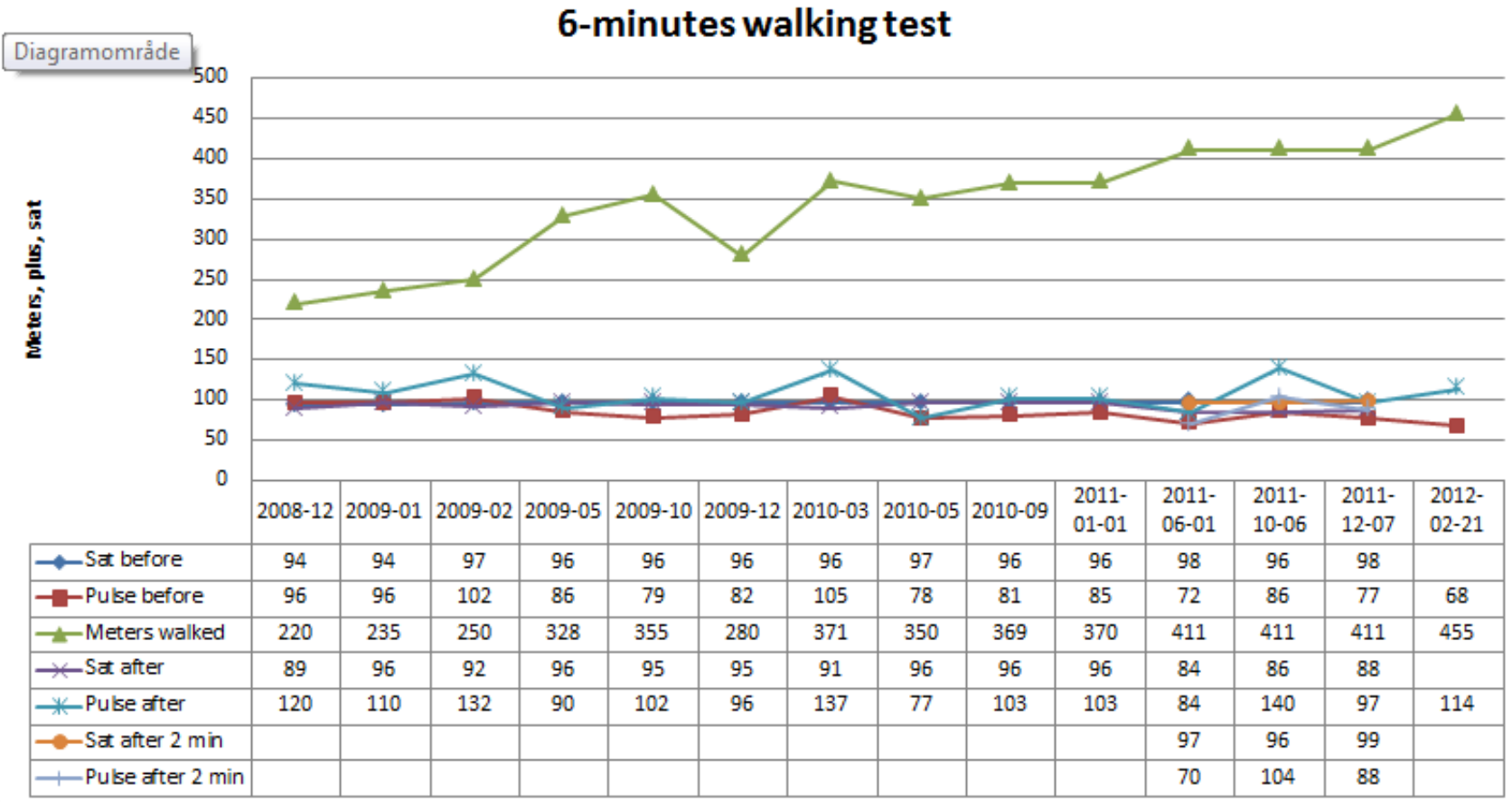
- Father to Elliot
 - Born 2005 and diagnosed with PAH 2007
 - Lung transplanted in 2014
- President of the Swedish PH association since 2011



Endpoints – personal experience

- Clinical endpoints on a regular basis was 6 MWD and echo.
- As parents we became experts in monitoring our child and creating own micro endpoints in the daily life.
- Together with the school we worked with an energy diary to monitor the energy level during the day.
- The more he was affected by PAH, the more we monitored at home.

Elliots 6 MWD



Energy diary

When	Who	Monday	Tuesday	Wednesday	Thursday	Friday	
1. In the morning)	Parent	4	4	5	2	4	19
2. After the first break in school	Teacher	2	2	2	3	4	13
3. Before lunch 1	Child	3	5	3	3	5	19
4. Before lunch 2	Child	3	3	3	4	4	17
5. Before lunch3	Child	3	1	3	3	4	14
6. After the lunch break	Teacher	2	2	2	2	3	11
7. Afternoon	Child	1	1	3	3	5	13
8. Afternoon after break	Teacher	2	2	3	2	3	12
9. Leaving school	Parent	4	2	5	2	4	17
10. Eveninging	Parent	4	4	4	4	4	20
		28	26	33	28	40	

1=Lot of energy 5=No energy

What is quality of life?



Created by Gan Khoun Lay
from Noun Project

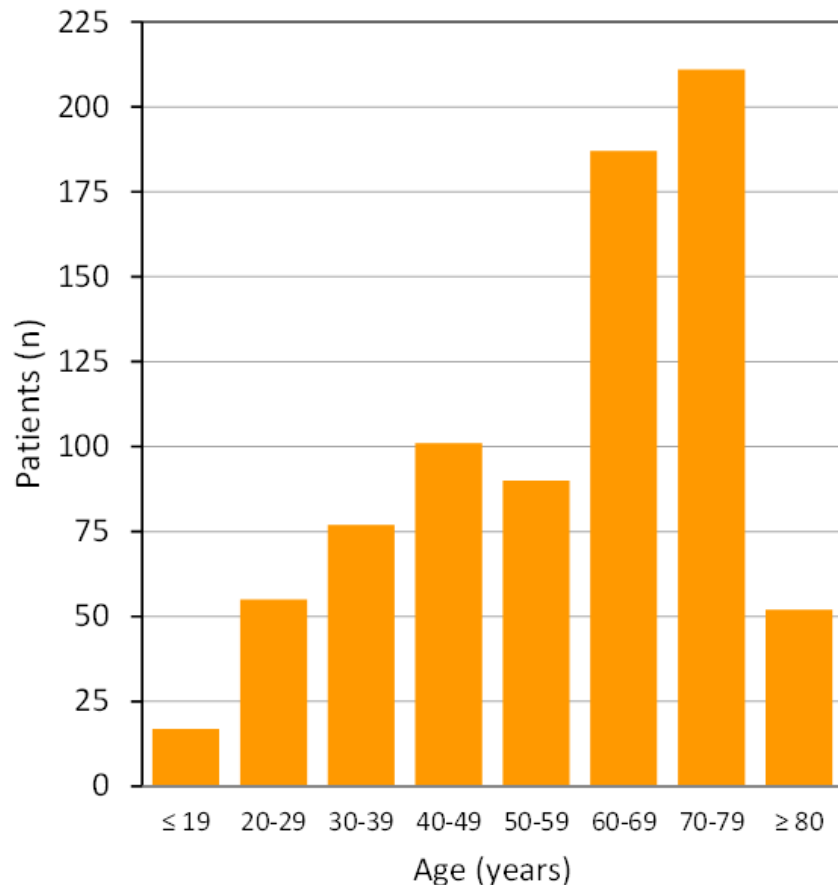


Created by Oksana Latysheva
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”To me, quality of life is about finding strategies, so that life becomes more than just worrying about my child”

From a parent to a child with PAH

Organization of the PAH care for children



Age of the patients in the national registry in Sweden

- 7 PAH centers in Sweden for adults
- The centers report to the national PAH registry
- No PAH-specialists for children
- Children with PAH are "invisible"

Insights

- Important to find ways how to transform the observations at home to structured data to share with PAH specialists
- Access to professional PAH support is very important for the families and the child

Thank you!

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