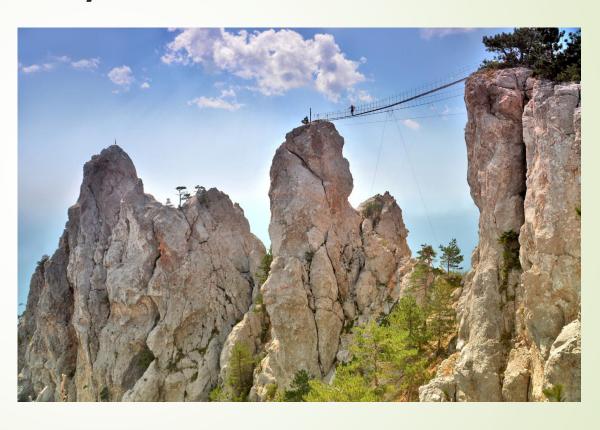
Physical therapy for individuals with Rett syndrome



Prof. Meir Lotan, France, 2023

First thing first





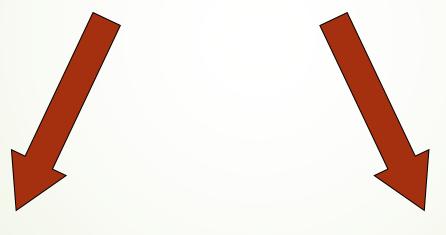
- The French association for inviting me here
- The children and families with RS
- My Co-workers

What are the topics for today

- What is physical therapy (PT)
- What is PT for Rett syndrome
- Case study
- take home message

Definition of PT

The treatment of disability by physical and mechanical means (as massage, regulated exercise, water, light, heat, and electricity)

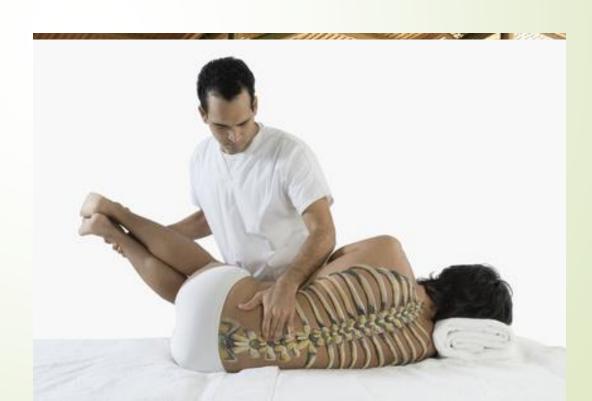


Direct therapy

Direct therapy – hands on

- Bobath
- Vojta
- **■**Feldenkrais
- **■**Yoga
- Snoezelen
- Light therapy
- Massage

- Hydrotherapy
- Hippotherapy
- Osteopathy



Physical therapy?

- ■It not about the title "Physical Therapy"
- Is about seeing the child and family's needs!!!

















Physical therapy

- It not about the name
- Is about seeing the child family's needs!!!
- There is no right Goforit
- If its goog
- ■If its good
- ■If you see result

Dir

.BUT

24/7 intervention?

The child with RS is awake 100h/w

- •2X half an hour physical therapy
- •2X half an hour occupational therapy
- •2X half an hour hydrotherapy
- •2X half an hour speech therapy
- •2X half an hour music therapy

Just 5% therapy of each child's waking hours

Build and apply a daily curriculum

	Sun	Mon	Tue	Wed	Thu	Fri
08:00	Hydro	Physio		Hydro	Physio	
09:00	_	SPE	CIAL	CHA	\IR	
10:00						
11:00				KING		
12:00		on in E	11 11 11 11 1			
13:00		3)			IR	
14:00		STAND				

- Build and apply a daily activity program
- Measure for TheraTogs



- Build and apply a daily activity program
- Measure for Theratogs
- Arrange a Treadmill program



- Build and apply a daily activity program
- Measure for Theratogs
- Arrange a Treadmill program
- Consult on a seating system



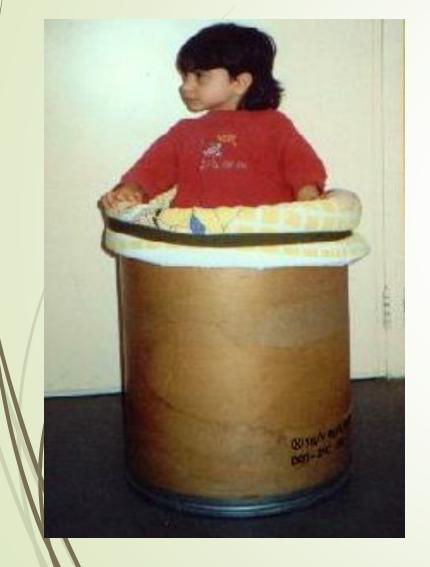






- Build and apply a daily activity program
- Measure for TheraTogs
- Arrange a Treadmill program
- Consult on a seating system
- Assistance in finding the right device

What is the right device?









- Measure for Theratogs
- Arrange a Treadmill program
- Consult on a seating system
- Assist in finding the right device
- Think about postural alignment
- Construct an intensive program

Its **not** about money



Improve hand function







Improve manual sensory input



Maintain back rang of motion

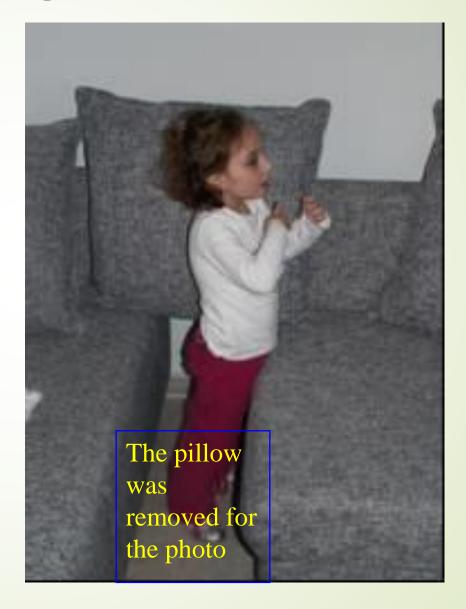


Strengthen back muscles



Improve standing ability





Just published - A severity comparison between Italian and Israeli Rett syndrome cohorts

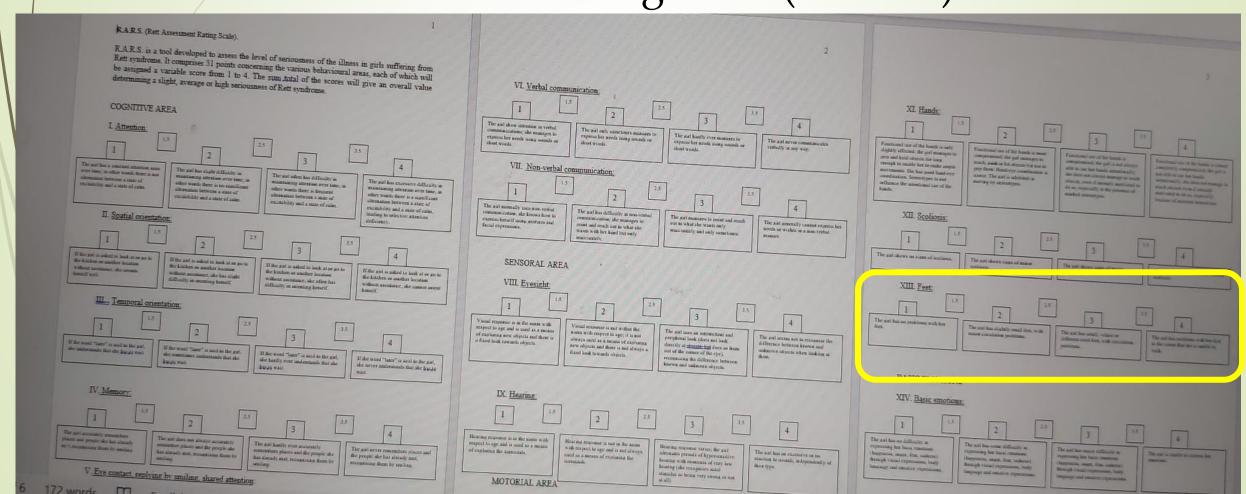
■ 136 Italian children and woman with RTT

Vs.

- ► 59 Israeli girls and women with RTT were assessed.
- There were no significant differences in age and genetic mutations

Just published - A severity comparison between Italian and Israeli Rett syndrome cohorts

■ The Rett Assessment Rating Scale (R.A.R.S) was used



 1

 1.5

 2.5

 3.5

 3.5

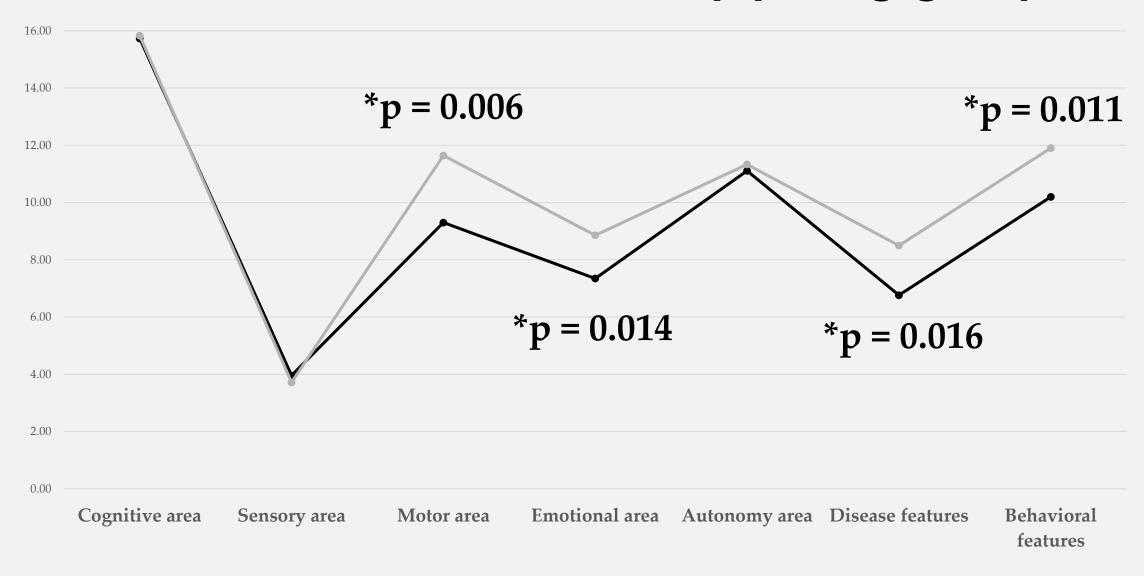
The girl has no problems with her feet.

The girl has slightly small feet, with minor circulation problems.

The girl has small, valgus or different sized feet, with circulation problems.

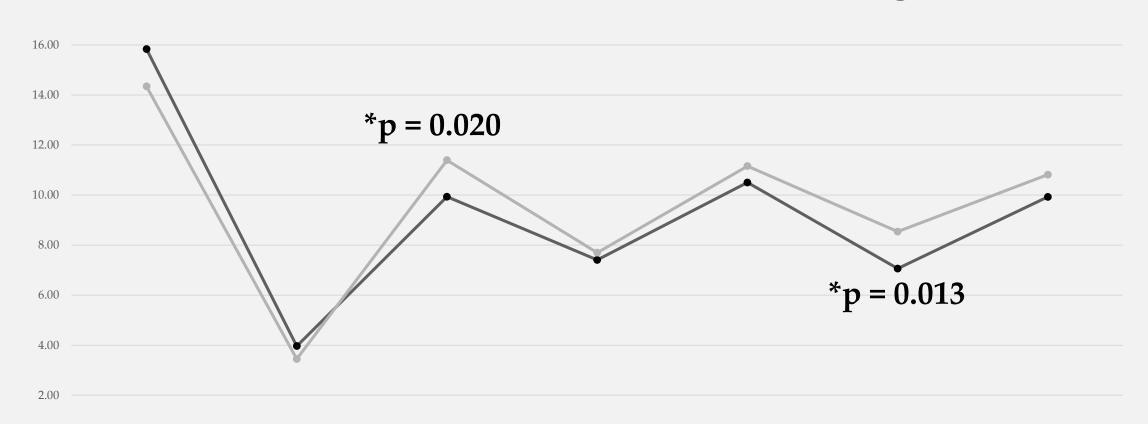
The girl has problems with her feet, to the extent that she is unable to walk.

Differences in Rett severity young group



+Italian U11 group -Israeli U11 group





Cognitive area

18.00

0.00

Sensory area

Motor area Emotional Autonomy area area

Disease features **Behavioral** features

→Italian U40 group

-Israeli U40 group

Explanations and Conclusions

The Italian group is **better** in most areas!!!

WHY?

- The difference lies in the educational system
- In Italy: The girls are enrolled in mainstream schools (integrated system) half a day and than they go home.
- ■In Israel: The girls go to special education centers (segregated system). The child is at school until 17:00, gets home at 18:00.

Pros and cons

	Get a lot of social interaction	The child get a full array of treatments at school	The child is very active in the afternoon	Both parents can maintain a full- time job
Italian	+		+	
Israeli	_	+	-	+

Activity is about finding a motivational factor



A case study

- C.B. a 7 years old
- She enters the therapy room walking while held by her mother and care giver each holding one of her arms.
- She had a potential to improve her functional ability









Next steps







Next steps







Where do you want your child to be?

The functional level of your child with Rett Syndrome

So, what can physical therapy offer for Rett

- Anti scoliotic intervention
- ► FACT "Functional Alignment Core training" intervention
- Walking
- Regaining walking in RTT
- Fear of movement



So, what can physical therapy offer for Rett

- Anti scoliotic intervention
- ► FACT "Functional Alignment Core training" intervention
- Walking
- Regaining walking in RTT
- Fear of movement
- Prevention of hip dislocation
- Advice about Sitting possibilities
- Positioning

So, what can physical therapy offer for Rett

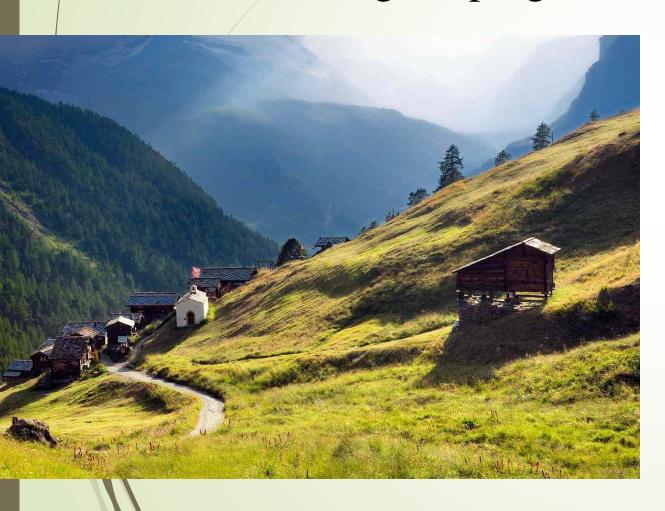
- Remote rehabilitation
- Horse-back riding
- Hydrotherapy
- Treating Apraxia
- Treating Ataxia
- Reducing constipation
- Maintaining general health

Summation - Take home massage

- Physical activity is essential for individuals with Rett syndrome
- It can be presented as direct therapy or indirect therapy
- But its not about getting physical therapy
- Its about getting her to be as active as possible
 - Its about an on-going program

Summation - Take home massage

■ Its about fitting the program to her environment





Summation - Take home massage

- Its about fitting the program to her environment
- Its about inserting her motivations within the program
- Its about finding a balance and (parents, family, siblings, therapist)
- The program has to be adjusted to the child needs and ability
- It has to be adjusted to the family resources
- It has to bear results

Bibliography

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Thank you for listening

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