



## *Transition times.*

*Supporting the child and adolescent's transitions in Pediatric condition*

2<sup>nd</sup> S.I.P.Ped. International Conference

November 7 – 9, 2019

Palermo, Sicily, Villa Magnisi, Ordine dei Medici Chirurghi e Odontoiatri



# ***Developmental transitions of children with congenital heart disease: from childhood to middle adulthood***

**2<sup>nd</sup> International  
Meeting SIPP**

**7-9 Nov.  
2019,  
Palermo**

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Adolescent Psychiatry, Rotterdam  
University of Amsterdam/ the Bascule  
The Netherlands**

## Developmental challenges CONHD

Developmental Tasks	Consequences ConHD
<b>Infancy</b>	
Attachment/ sense of trust	Hospitalization/life threatening surgery
Sensorimotor experiences	Restricted movements/exhausted
Deprived nurturing	Parental stress, grief Overprotection
<b>Toddlerhood</b>	
Develop autonomy	Dependency on parent
Locomotor/language skills	Limited opportunity
Sensorimotor/ Preoperational thought	Painful experiences Pampering/ less limit setting

**Developmental  
challenges  
CONHD**

**Preschool**

Master self-care skills	Limited opportunities
Begin peer relationships	Play with younger kids
Sense of body image	Pain, “different”
Magical thinking	Guilt (I am punished)

**School Age**

Sense of accomplishment	Limited opportunities : - school absences /gym - tired
Form peer relationships	
Concrete operations thinking	-misunderstanding limitations/ treatment

**Developmental  
challenges  
CONHD**

## Adolescence

Personal /sexual identity

Feeling different  
Less able to compete

Autonomy

Dependency on family;  
limitations job/career  
Limited opportunities

Sexual relationships

Fear rejection/scars  
Anticonception/heredity

Abstract thinking

“Why me”? Future/ life  
expectancy

Health care/Transition



# 1990



**cohort 1**  
**< 1980**



**10**



**20**



**30**

**cohort 1**  
**< 1980**



cohort 1



# Psychopathology



27%



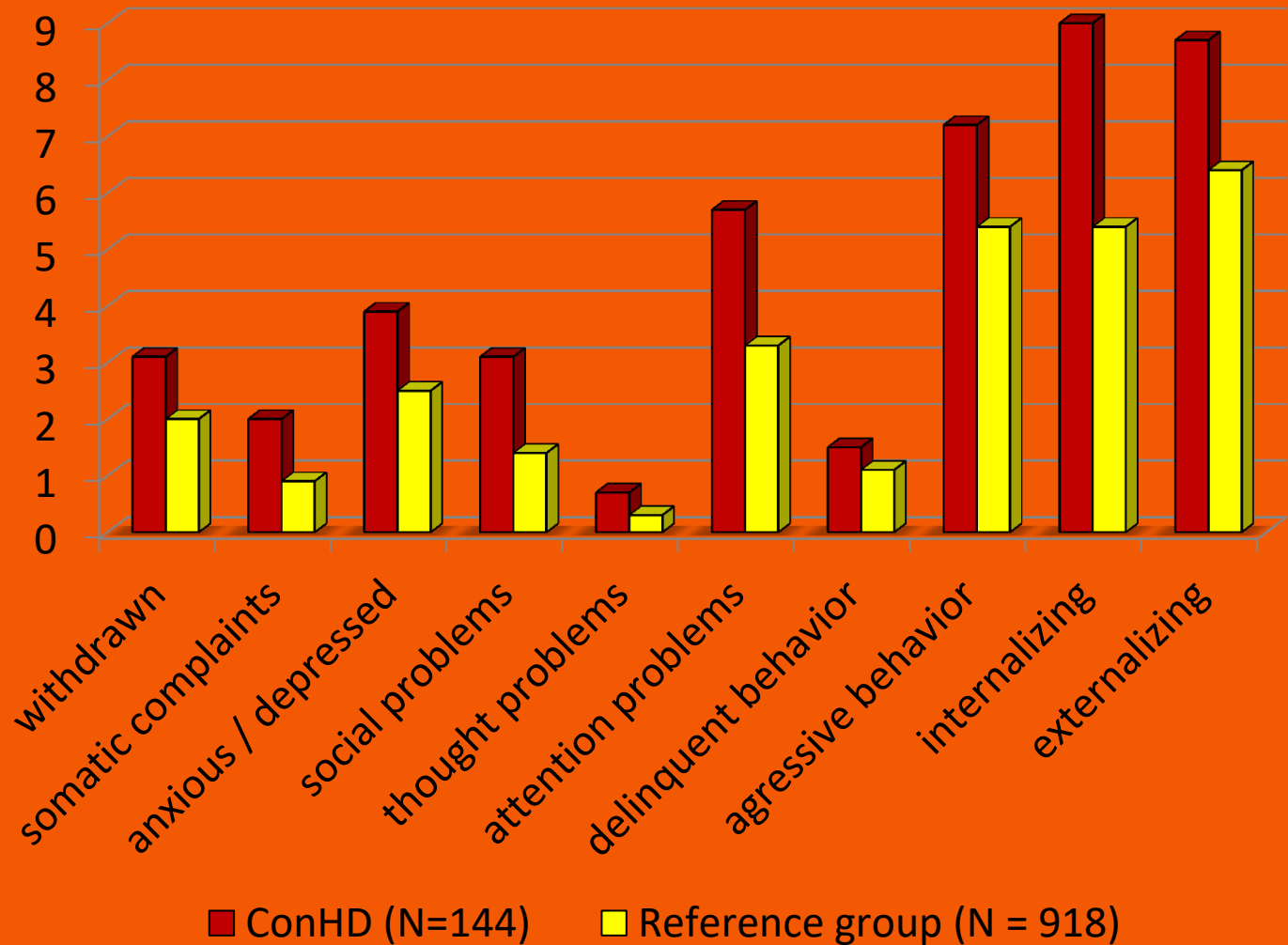
Norm 10%



cohort 1



# CBCL parent report – mean problemscores



cohort 1

20



cohort 1

20



cohort 1

30





cohort 1

30







cohort 1



cohort 1

30



## Cohort 2 > 1990





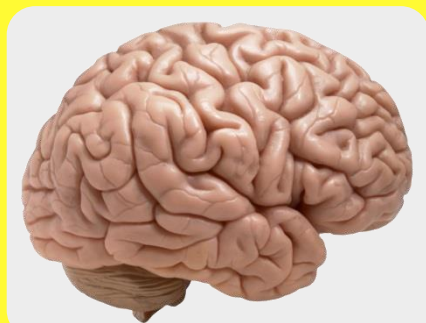


**cohort 2**  
**> 1990**





**cohort 2**  
**> 1990**







**cohort 2**  
**> 1990**



## *Original Article*

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# Psychosocial needs of children undergoing an invasive procedure for a CHD and their parents

Eveline M. Levert,<sup>1</sup> Willem A. Helbing,<sup>2</sup> Karolijn Dulfer,<sup>1</sup> Ron T. van Domburg,<sup>3</sup> Elisabeth M. W. J. Utens<sup>1</sup>

*Cardiology in the Young* (2018), 28, 192–198  
doi:10.1017/S1047951117001378

© Cambridge University Press, 2017

## *Guidelines*

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# Multidisciplinary family-centred psychosocial care for patients with CHD: consensus recommendations from the AEPC Psychosocial Working Group

Elisabeth M.W.J. Utens,<sup>1,2,\*</sup> Edward Callus,<sup>3,\*</sup> Eveline M. Levert,<sup>1</sup> Katya De Groote,<sup>4</sup> Frank Casey<sup>5,6,‡</sup>

# Inter- ventions: Preschool



## CHIP-Family

Van der Mheen et al.,  
Utens, 2019

*Cardiology in the Young*

[cambridge.org/cty](https://cambridge.org/cty)

Original Article

CHIP-Family intervention to improve the psychosocial well-being of young children with congenital heart disease and their families: results of a randomised controlled trial

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# CHIP-Family for ConHDchildren (4-7 yrs) and families

(McCusker et al. 2012; van der Mheen, BMC Pediatr.,2018)



## Children with CHD:

emotional, behavioral, school, cognitive, social, sport problems

(Karsdorp et al. 2007, Riehle-Colarusso et al. 2015,  
Spijkerboer et al. 2008, Duppen et al. 2013)

## Parents of children with CHD

- Parental functioning important mediator

(Casey et al. 2010; Bellinger et al. 2009 )

- ↑ ***psychosocial problems***

(McCusker et al. 20120 )

# CHIP-Family group: parents

## **Problem prevention therapy**

"my husband doesn't support me",  
"my child feels different", etc.

## **General parenting skills**

discipline, communication, motivation...

## **Specific parenting skills**

school absence, medical interventions...



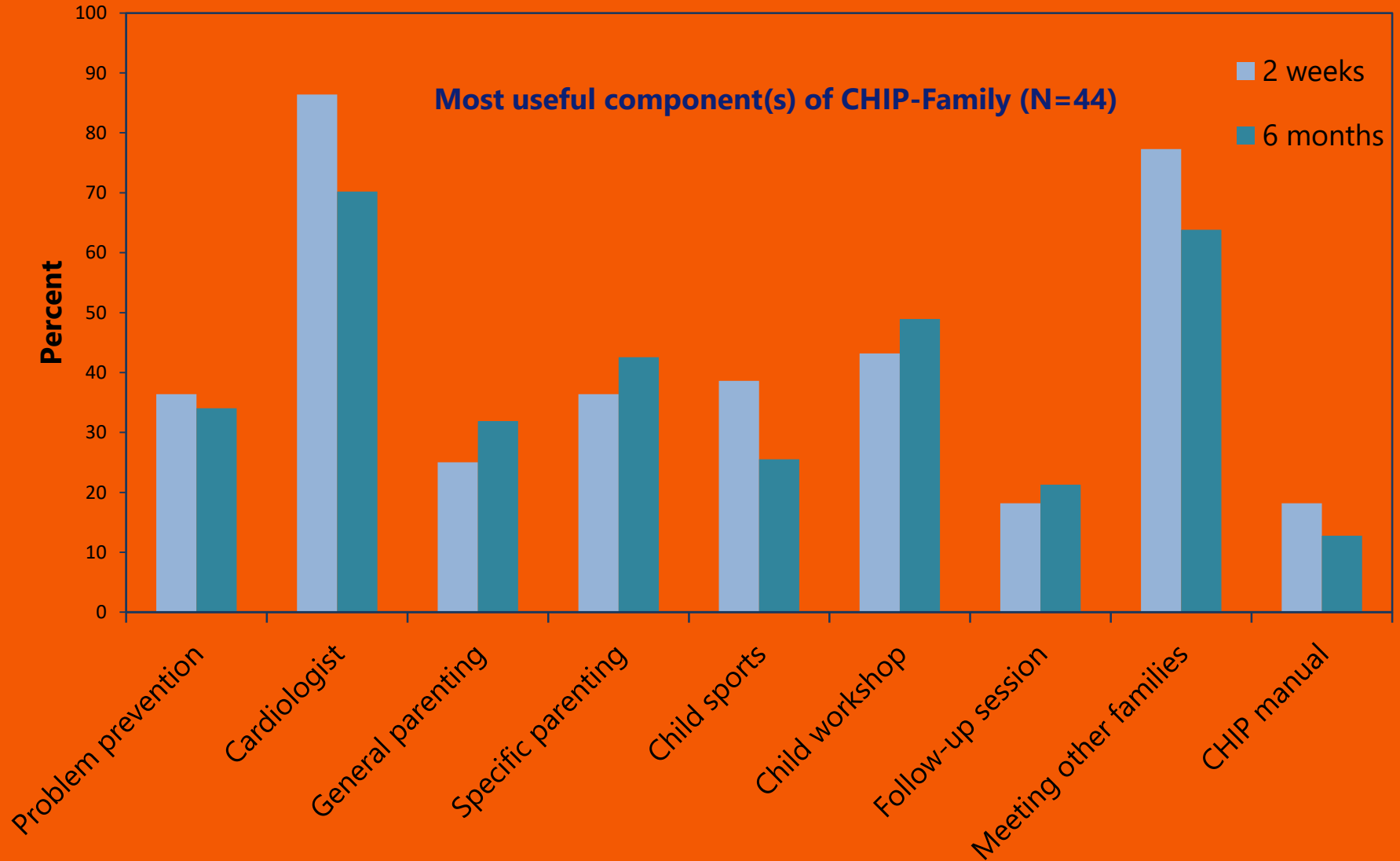
# CHIP-Family group: 4-7 years

- CBT Fun FRIENDS protocol *Pahl & Barrett, 2010*
- Thoughts – feelings – behavior



# CHIP-Family: social validity

Most useful component(s) of CHIP-Family (N=44)

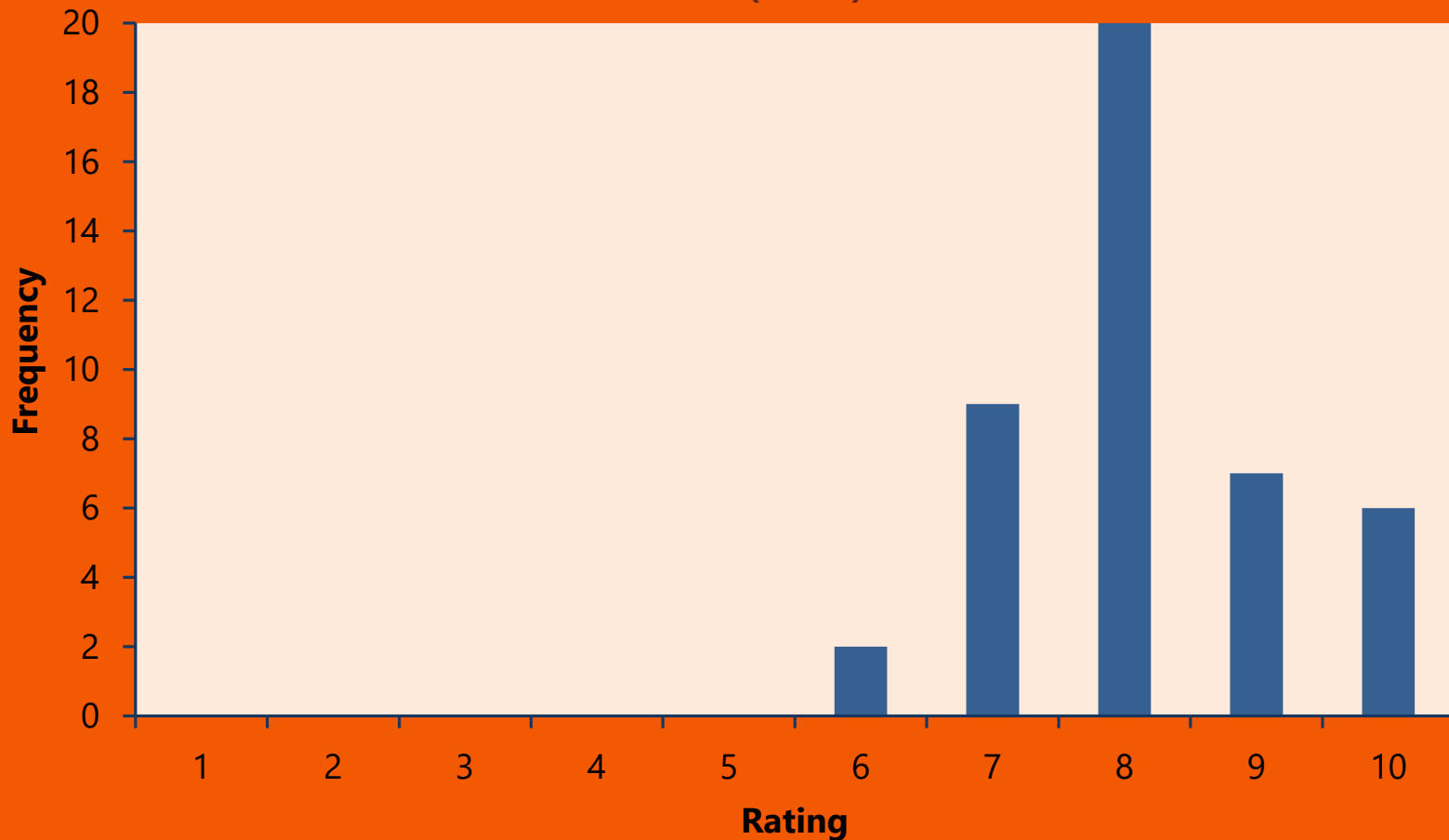


# CHIP-Family

Mheen et al. Cardiol in the Young 2019

**Would you recommend CHIP-Family to other families?**

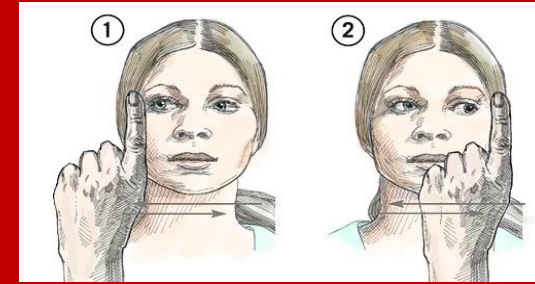
(N=44)



# Interventions: School



**E**ye  
**M**ovement  
**D**esensitization &  
**R**eprocessing



EUROPEAN JOURNAL OF PSYCHOTRAUMATOLOGY  
2018, VOL. 9, 1536287  
<https://doi.org/10.1080/20008198.2018.1536287>



EUROPEAN JOURNAL OF  
**PSYCHO-  
TRAUMATOLOGY**  
THE OFFICIAL JOURNAL OF THE EUROPEAN SOCIETY FOR TRAUMATIC ENDOGENIC STUDIES



**Taylor & Francis**  
Taylor & Francis Group

STUDY PROTOCOL

 OPEN ACCESS



**Eye movement desensitization and reprocessing (EMDR) in children and adolescents with subthreshold PTSD after medically related trauma: design of a randomized controlled trial**

**Meentken et al.,  
2018**



**Hospital admission/medical procedure** (Schreier et al, 2005, Bronner et al., 2008)

**Clinical PTSD → 10%**

***Subthreshold PTSD = elevated symptoms → 35 % !***

***underestimated → functional impairment/distress!***

(Ziegler et al, Pediatrics 2005; Carrion et al., JAACAP, 2012)

**If untreated: anxiety/depression, long-term psychiatric morbidity, dropout from school/work, medical consumption ↑, adherence ↓, unfavorable medical outcomes** (Stallard,2006; Cohen et al, 2004, Cart et al, 2012),

***Secondary prevention. RCT: EMDR vs CAU, ConHD 6-12 yrs.***





EMDR was superior in reducing...



MEDICAL PHOBIA



SLEEP PROBLEMS



DEPRESSION



# Adolescence

- **T** Tattoos, piercings and antibiotic prophylaxis
- **E** Education
- **E** Exercise
- **N** Need life long care
- **A** Access to care and insurance
- **G** General health
- **E** Employment
- **R** Relationships
- **S** Smoking, alcohol and drugs

MEF transition 2019



*Adapted from the Got Transition Initiative*

Please fill out this form to help us see what you already know about your health, using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Today's Date (mm/dd/yyyy):

Name (Last/First):

Date of Birth (mm/dd/yyyy):

### Transition and Self-Care Importance and Confidence

*On a scale of 0 to 10, please circle the number that best describes how you feel right now*

Please rate how confident you feel about taking charge of your heart health care

0 (Not)	1	2	3	4	5	6	7	8	9	10 (Very)
------------	---	---	---	---	---	---	---	---	---	--------------

Please rate how confident you feel moving to adult-focused heart care

0 (Not)	1	2	3	4	5	6	7	8	9	10 (Very)
------------	---	---	---	---	---	---	---	---	---	--------------

My Health

*I need to learn*



My Health			
Please check the box that applies to you right now.	Yes, I know this	I need to learn more	Not applicable
I understand the long term potential issues associated with my heart condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know why I should take my medications (what they are supposed to do)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what cardiac symptoms require more urgent medical attention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what my typical vital signs should be (heart rate, blood pressure, oxygen saturation) and I have a copy of my electrocardiogram (EKG)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wear a medical alert bracelet or tag to indicate my cardiac condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what kinds of physical activity (exercise) are safest and healthiest for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what kinds of food (diet) are safest and healthiest for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know about medicines or supplements that could interfere with my heart medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know if and when I should take antibiotics prior to dental procedures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that I should talk to my heart doctor about traveling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know that I should talk to my heart doctor before I start having sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the impact of high-risk behaviors (tobacco, alcohol, illicit drug use, tattoos, and unprotected sex) on my heart and overall health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how my heart and cardiac care needs might change in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain my heart problem (congenital heart disease) to another person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





Date Completed:			Date Revised:		
Form completed by:					
<b>Contact Information</b>					
Name:			Nickname:		
DOB:			Preferred Language:		
Address:					
Cell #:		Home #:		Best Time to Reach:	
Email:			Best Way to Reach:    Text    Phone    Email		
Health Insurance Plan:			Group and ID #:		
Cardiologist (1):		Location:		Phone:	
Cardiologist (2):		Location:		Phone:	
<b>Emergency Care Plan</b>					
Emergency Contact:		Relationship:		Phone:	
Preferred Emergency Care Location:					
Procedural Antibiotics Recommended (Endocarditis Prophylaxis): <input type="checkbox"/> Yes <input type="checkbox"/> No					
Common Emergent Presenting Problems		Suggested Tests		Treatment Considerations	
Special Considerations:					
<b>Allergies</b>					
Allergies		Reactions			
<b>Diagnosis and Current Problems</b>					
Problem		Details and Recommendations			
Primary Cardiac Diagnosis:					
Secondary Diagnoses:					
<input type="checkbox"/> Pulmonary					
<input type="checkbox"/> Renal					
<input type="checkbox"/> Liver					
<input type="checkbox"/> Neuro-developmental					
<input type="checkbox"/> Genetic					
<input type="checkbox"/> Contraception					
<input type="checkbox"/> Hematologic/Anticoagulation					
<input type="checkbox"/> Psychologic					

# Take home message

***Development of evidence based  
psychosocial interventions !!  
Early prevention and intervention***



Take home message  
*Development of evidence based effective interventions!!*

*Early psychosocial prevention and intervention*



2<sup>nd</sup> International  
Meeting SIPP

7-9 Nov.  
2019,  
Palermo

Thank you for  
your attention!

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funded by the Netherlands Heart Foundation

