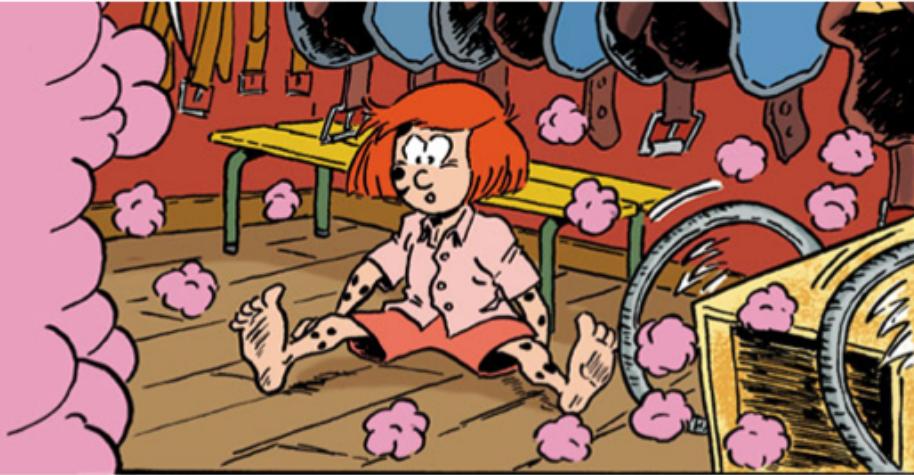




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Nevus International  
Paris 12 septembre 2018  
Psychosocial team

Naevus



**Docteur Béatrice de REVIRS  
Leader of psychosocial team  
Présidente ANNA ASSOCIATION  
Translation : Krystopher RICHERT**

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Coordonnateur de l'équipe de direction (London)



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**Leader of scientific network**  
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**Mrs Marjolein van Kessel**  
**Leader of patient support group network**  
Working group:  
Corrado Giani  
Sieglinda McKeown  
Paul Coleman M.  
Pedro Rolando Lopez



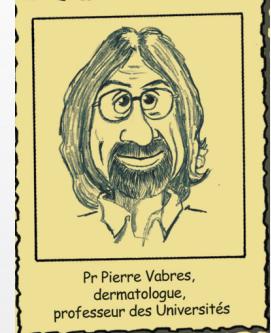
**Mrs Jodi Whitehouse**  
**Leader of communications team**  
Working group:  
Kathy Wright  
Michelle Sibbons



# Définition du Handicap Esthétique

- « Le handicap esthétique correspond à toute différence morphologique visible (y compris lorsqu'elle est habituellement dissimulée au regard) entraînant chez la personne qui en est atteinte une limitation de son bien-être en société du simple fait de sa visibilité, même si elle n'entraîne pas d'autre conséquence. »

Pr P. Vabres



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## **Cosmetic Disability definition**

"Cosmetic disability can be defined as any type of visible difference which results in the limitation of wellbeing and/or of social interaction, only as a result of its appearance, and irrespective of additional health problems that it may cause."

# Equipe d'ANNA



- **Présidente :**

- Dr. **Béatrice de Reviers**, Médecin généraliste, diplômée en thérapies comportementales et Cognitives (Université Paris Descartes), Paris

- **Vice Présidents :**

- **Prof. Pierre Vabres**, dermatologue pédiatrique, Centre de référence MAGEC, site Dijon-Mosaïques  
Equipe de recherche GAD - INSERM UMR1231 LNC  
Université de Bourgogne, UFR Sciences de la Santé  
Fédération hospitalo-universitaire TRANSLAD  
Service de Dermatologie, Hôpital universitaire de Dijon, Dijon
- Dr. **Heather Etchevers**, embryologiste; Institut National de Santé et de Recherche Médicale (INSERM), Marseille

- **Trésorier:**

- **Philippe de Reviers**, expert-comptable et CAC, spécialiste des associations , Paris

- **Membres Fondateurs:**

- **Lorraine Joly**, psychologue clinicienne pour les maladies génétiques, Hôpital universitaire de Dijon, Dijon

- **Sandrine Massoni**, psychologue clinicienne, Paris

- **Hanane Douibi**, experte en nævus géant congénital; mère d'une famille concernée par le handicap esthétique, membre de l'Alliance Maladies Rares, Paris

- **Patrick Ballet**, dessinateur de la bande dessinée 'Tout un Cirque' (La Fourmillière BD, 2014) pour l'association Naevus 2000 France-Europe, Saint-Étienne

- **Loïc Ballet**, co-auteur de 'Tout un Cirque' et journaliste sur France 2, Paris

- **Florence Vabres**, orthophoniste, Dijon

- **Sonia Roux**, professeur de Français, Paris

- **Jean-Michel Reiter**, Post gouverneur Kiwanis France-Monaco and président de APEI, Paris



## With CMN :



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Two difficulties to overcome:

- ✓ To Accept that your body image does not meet your expectations or of those of your parents
- ✓ To deal with the reactions of others

# Psychological impacts of CMN



The emotions identified with disfigurements:

- Shame
- Social Anxiety
- Low Self-Esteem
- Self Consciousness
- Depression

**Be careful ! all children do not have psychosocial disorders. It all depends on their resilience.**



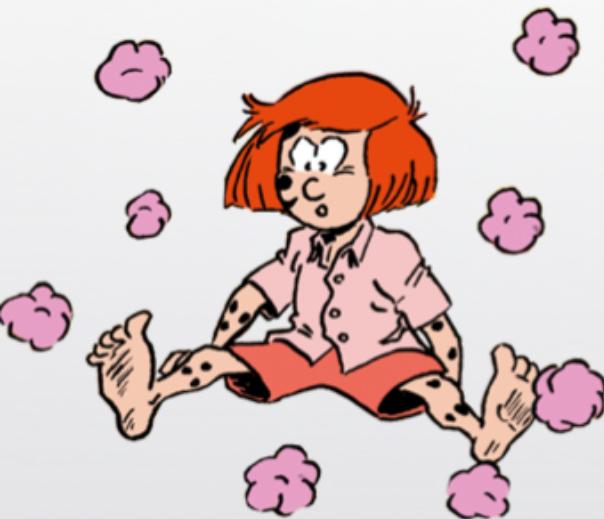


To Help build resilience Predictors of psychological distress	
Poor predictors of psychological distress	Good predictors of psychosocial distress
The clinical severity of the dysfigurement	<b>Coping strategies and the personal adaptation of these strategies</b>
The visibility of the malformation	<b>A person's experiences of stigmatization and bullying</b>
age	<b>Social support</b>
gender	How they perceive their malformation/ How they think others perceive their malformation

**working on the good predictors, we can often  
limit the developpement of secondary  
psychosocial disorders  
Resilience**



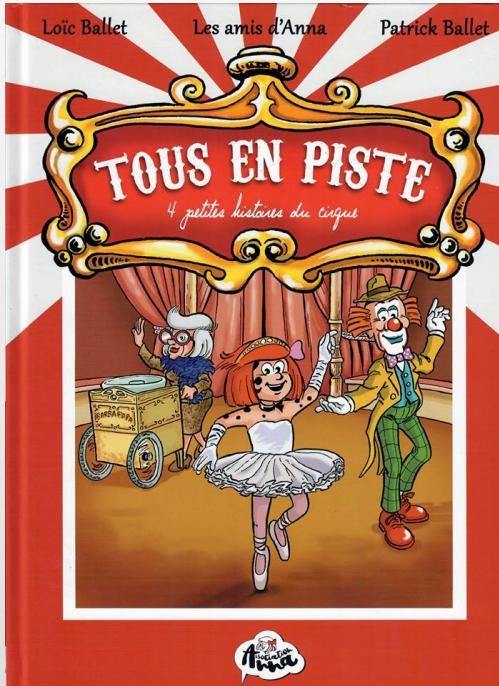
# So, What can we do ?



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Good predictors of psychosocial distress	Actions
Coping strategies and personal adaptation of these strategies	"En Piste" Programme implementation, comic book and Social interaction skills
Experiences of stigmatization and bullying	awareness workshops in schools
Social support	<ul style="list-style-type: none"><li>Young adults CMN owner group ( 18-35 years ).</li><li>Family support meetings.</li></ul>
How they perceive their malformation/ How they think other perceive their malformation	Individual therapy but other actions too

# “Tous En Piste” (On Stage)



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Comic book with 4 short stories

## General scenario:

- The main character is Anna with 2 companions : Ema and Arthur
- A time travel machine : that visits places and characters related to the history of circus and its documentation

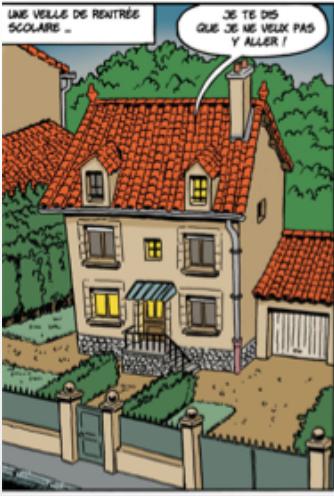
## Psychological scenario:

- Speaking with families we adapted the comic book to real life situations that families encounter
- Description self-help advice and strategies



## Jerk Filter

**“Life is an adventure, dare to live it”.**



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**Context:** anxiety for children at start of school year.

**Concepts addressed:**

- “**Jerk filter**”: It allows me to identify who I have in front of me.
- There are only two types of people : those who are part of the problem and those are part of the solution.
- identify your resource such as caring people like your parents, your family and those you can count on.



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# Trapèze

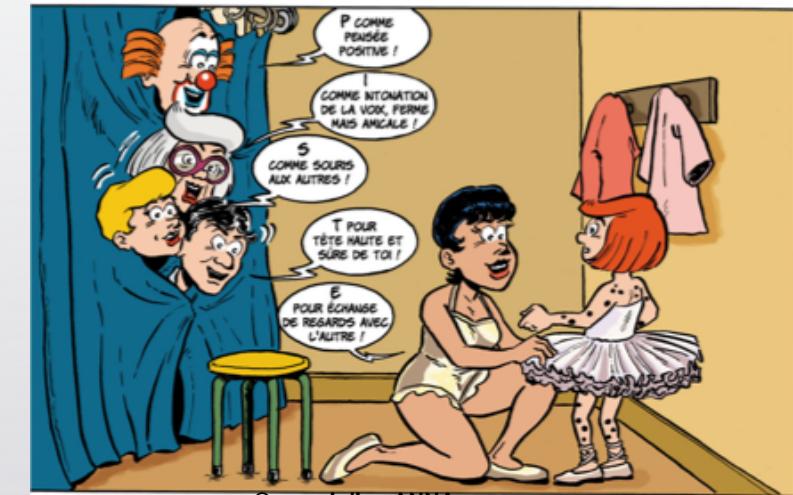
« Life is a challenge, meet it »

Context: the film trapeze at the winter circus  
Concepts addressed:

- How to deal with certain provoking situations?
- How to best prepare for those situations.
- « EN Piste » Strategy : our magic formula



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# Le clown Boom-Boom

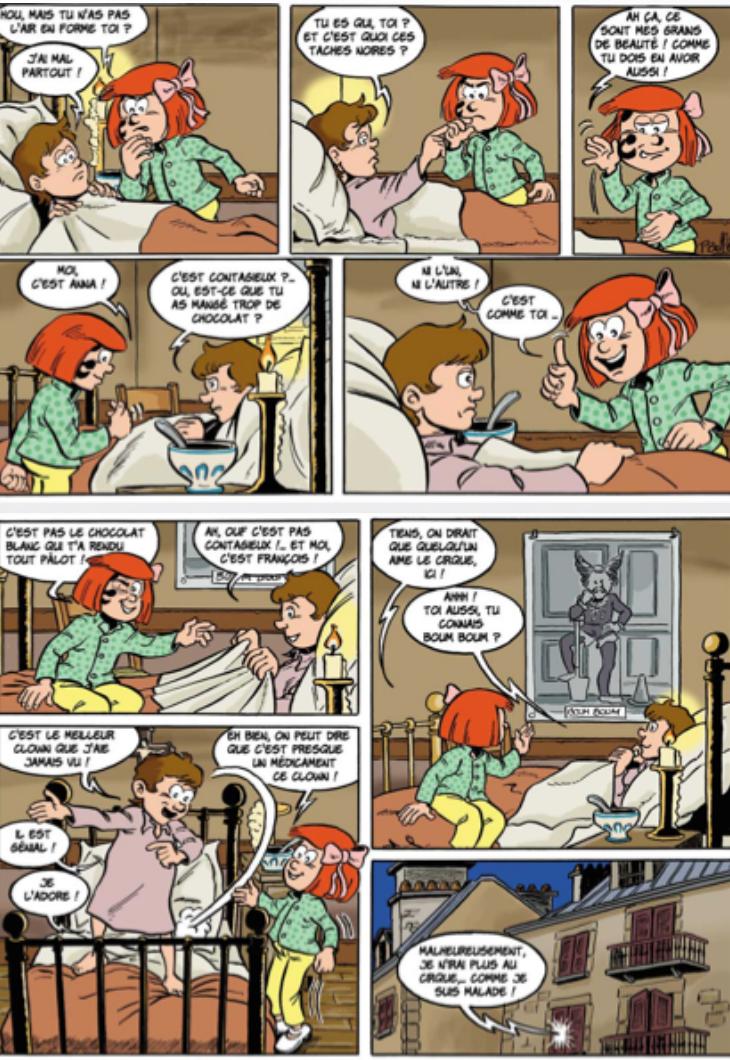
## « Life is mystery, get to know it »

Context : Clown Boom Boom

Concepts addressed:

- Learn to respond to the **natural curiosity** of people **without** aggressiveness
- **ERD strategy**: Explain in a simple and concise way my CMN, to Reassure and then Distract by changing the subject
- use **humour** whenever possible
- Keep in mind that your handicap requires you to adapt and explore **your abilities** to find original ways to get out of difficult situations.
- develop **empathy** for others in difficulty.

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# Girafe

« Life is a game, play it. »

Context : Girafe in palace's swimming pool

Concepts addressed:

- Learn to manage **nosy** people
- Learn : how to say **NO** and **put a STOP** to questions
- Assert your **dignity**
- To be allowed **not to have to answer questions** and be **respected** for that
- use **humour**

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## Buffalo Bill

### « Life is a dream, realize it »

**Context :** Buffalo Bill en Bourgogne

**Concepts addressed:**

- You are **a child** like any other
- You may happen to be curious when facing an other child with handicap. This curiosity is natural - So **stay charitable**.
- You are **not just a naevus**, you are also person.
- Never let it **take control of your life** and your family.

# So we can do it, this first school day

## « Life is a promise, fulfill it »



Context : The End !

Concepts addressed

- Parents' role.
- Gradually let the child gain **independance**.
- While still being at their side
- **The recipe** for happiness lies within in our comic book.  
Discover it yourself.

# ABC of a Nævus

## « Life is life, fight for it ! »

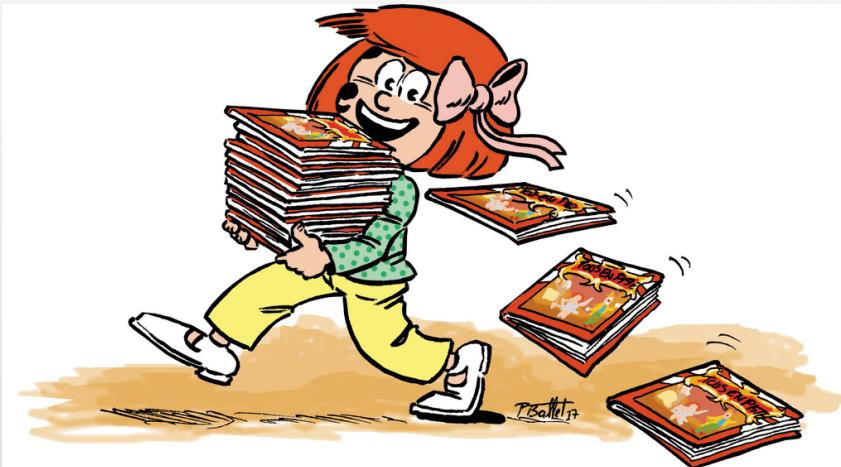


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# “En Piste” Programme

- Social interaction **skills training**
- Collective / group training
- Focus groups
- **Role play**
- Storyboards
- **Psychologists, doctors**
- Themes related to comic book stories
- **Evaluation:** Fondation Maladies Rares  
2017 grant application



# Workshop in a school



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<http://www.wonder-scolaire.fr/>

# We need you !

**1 kilo of rice + 1 kilo of rice = 2 kilograms of rice**

**1 Kilo of ideas + 1 kilos of Ideas = 25<sup>n</sup> kilos of ideas**

« You are between 18-35 years old.

You have a congenital giant naevus, and you have coped with a naevus.

So we need you, you have experience, dynamism, humour

You must not keep this treasure to yourself.

You want to pass on your tips.

youngsters and their parents are waiting for your tips and tricks to make the most of their daily lives and to look to the future with confidence.

If you have the desire to help : This group is for you !

Join us ! If you are a brother or sister with the same desire, then we also need your help too »



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**Thank you  
Let's get up and go !**

**Naevus**