TRANSITION RHUMATOLOGIE PEDIATRIQUE-ADULTE

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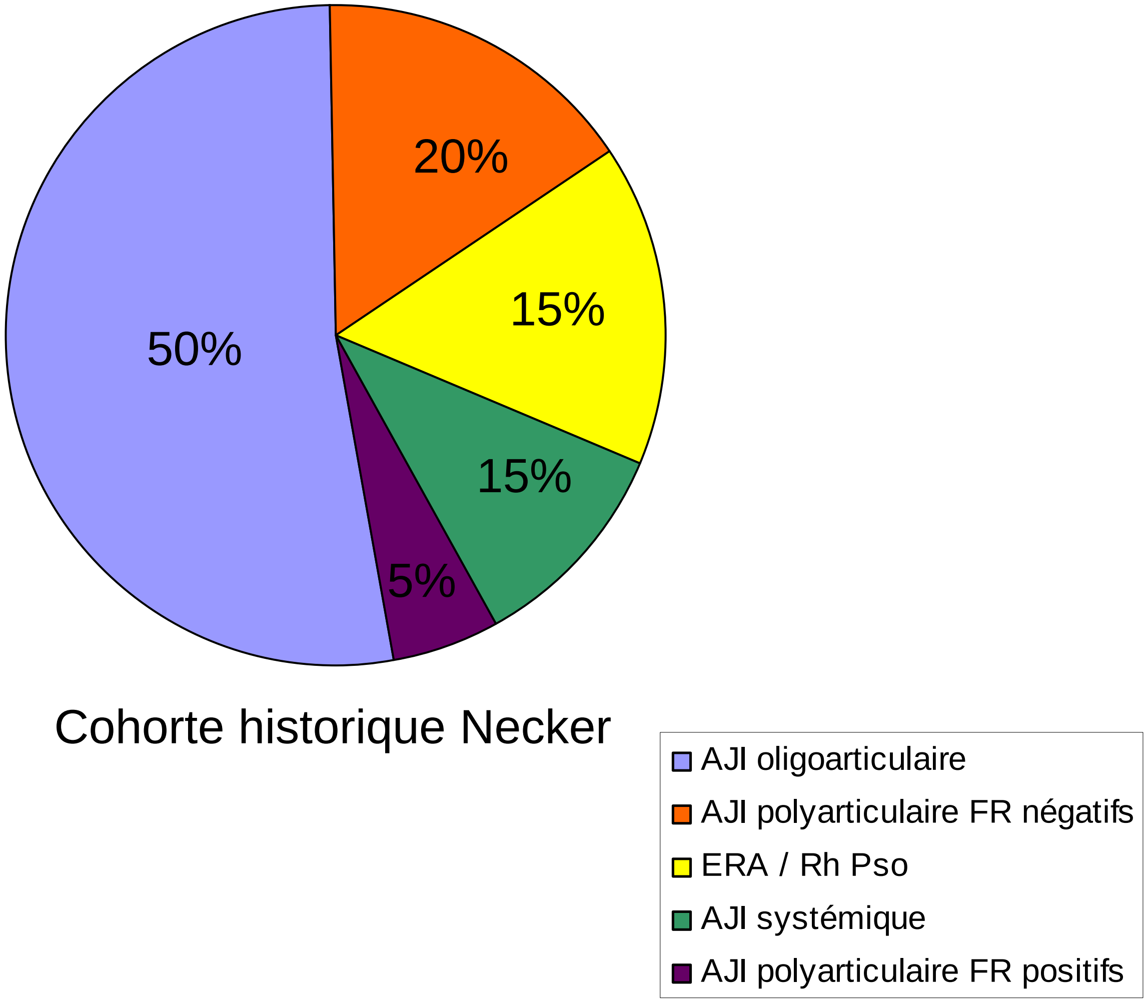
Service de Rhumatologie A, Hôpital Cochin

TRANSITION

- **Etat des lieux des JIA**
  - Idées anciennes ➔ pédiatrie ≠ adulte
  - Données récentes démontrent le contraire

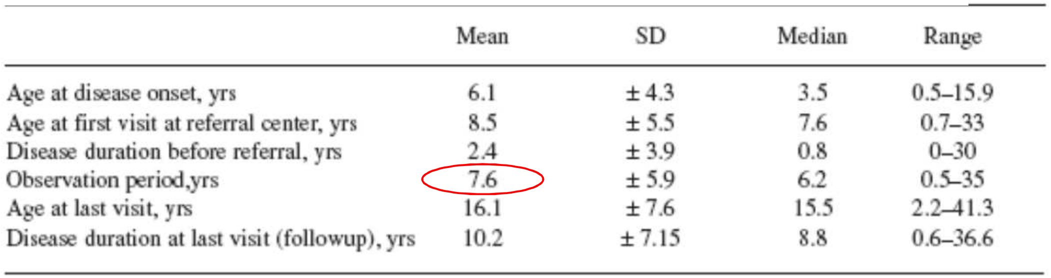
REPARTITION DES AJI



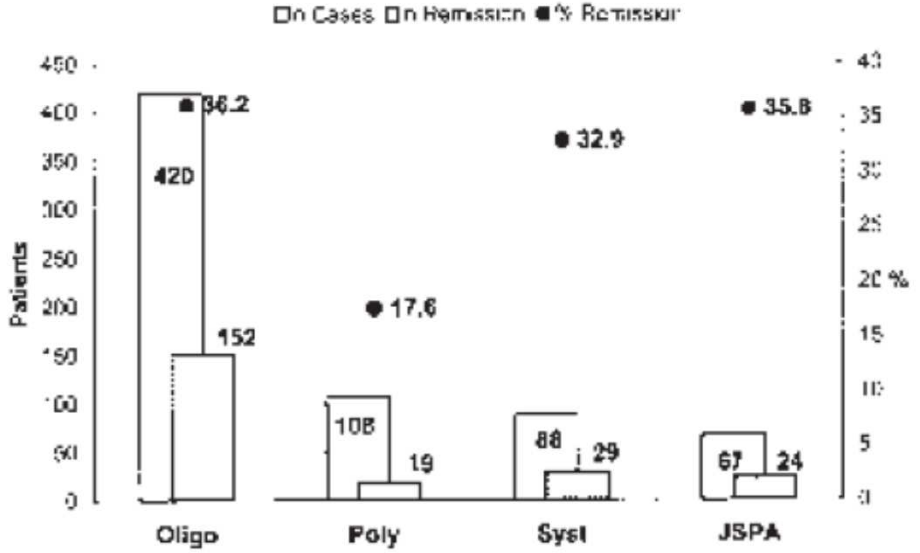
Cohorte historique Necker

REMISSION DES AJI

➔ 683 JIA dont 463 (68%) filles



	Mean	SD	Median	Range
Age at disease onset, yrs	6.1	± 4.3	3.5	0.5–15.9
Age at first visit at referral center, yrs	8.5	± 5.5	7.6	0.7–33
Disease duration before referral, yrs	2.4	± 3.9	0.8	0–30
Observation period,yrs	7.6	± 5.9	6.2	0.5–35
Age at last visit, yrs	16.1	± 7.6	15.5	2.2–41.3
Disease duration at last visit (followup), yrs	10.2	± 7.15	8.8	0.6–36.6

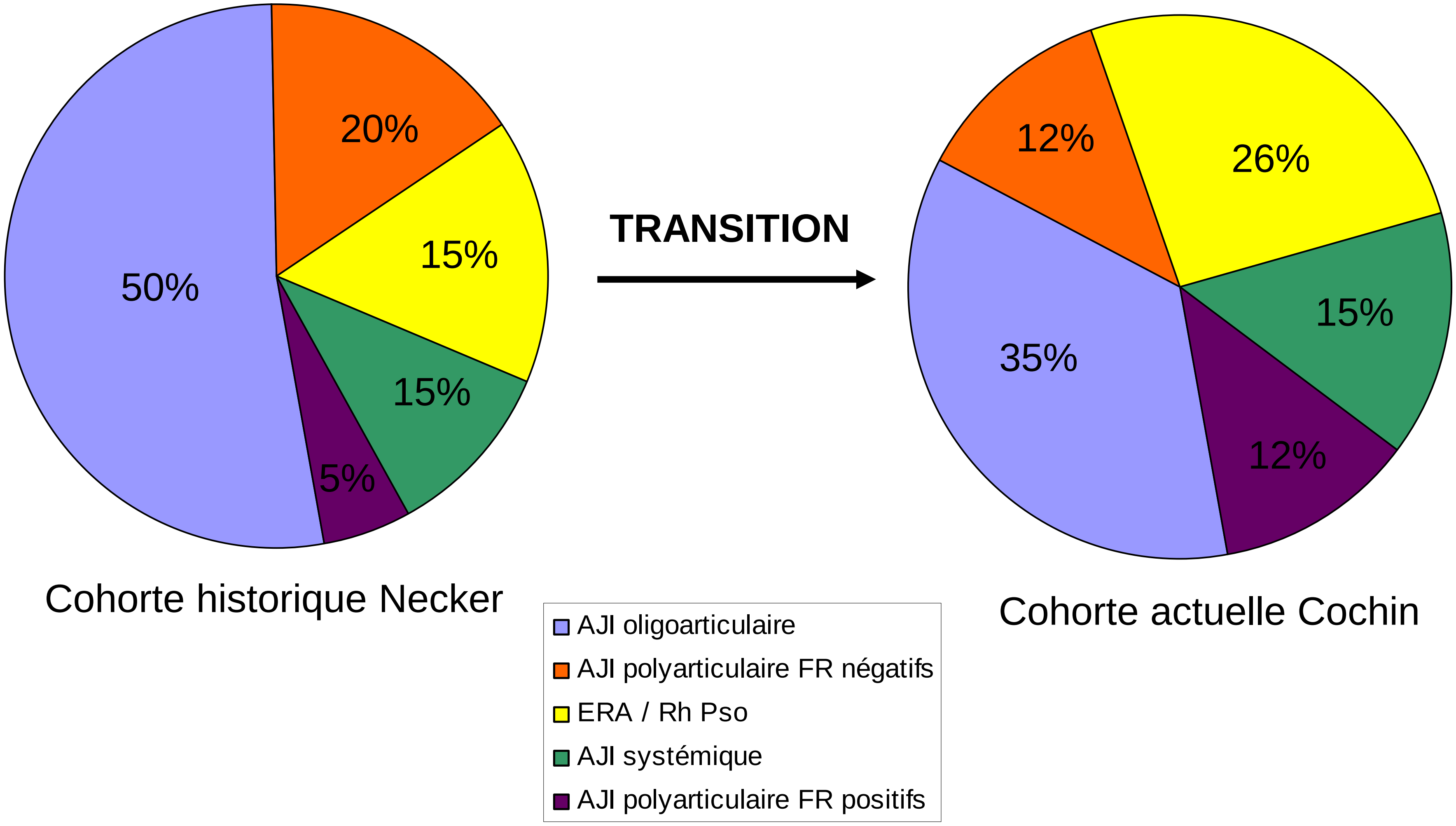


Fantini et al. J Rheumatol 2003

REMISSION DES AJI

	Nb de patients AJI	Age Range	Années de suivi	Rémissions
Minden 2000	**171**	**-**	**7.4**	**Oligo = 50%** **S = 38%** **Poly = 15%**
Foster 2002	**82**	**17-68**	**21**	**61% rémissions**
Minden 2002	**215**	**14-35**	**16.5**	**Oligo = 60%** **S = 54%** **Poly FR+ = 0%** **Poly FR- = 42%** **SpAj = 25%**
Oen 2002	**392**	**8.6-35.8**	**13.5**	**Oligo = 60%** **S = 45%** **Poly FR+ = 3%** **Poly FR- = 25%** **SpAj = 25%**
Arkela 2005	**123**	**21-26**	**16.2**	**37% rémissions**

REPARTITION DES AJI



REMISSION DES AJI

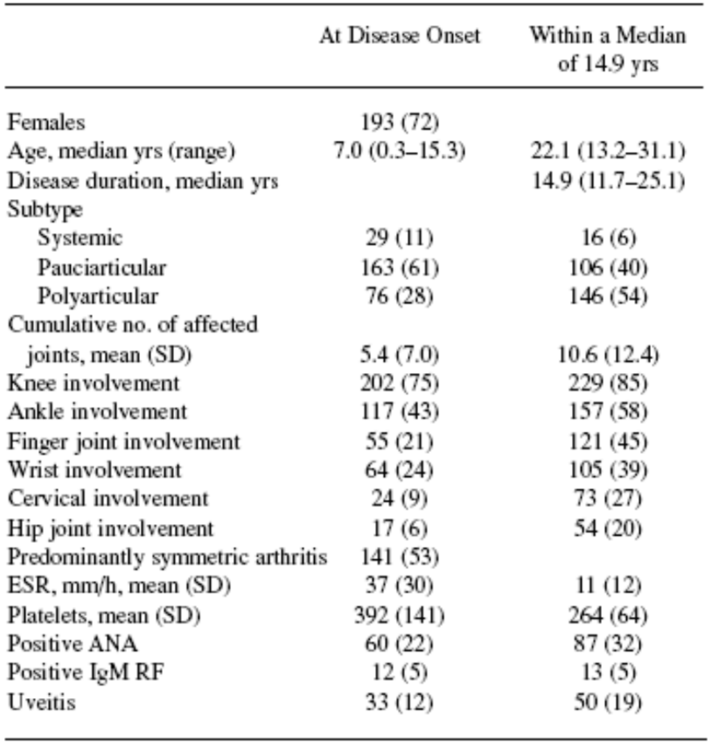
Donc >50% en moyenne des AJI restent actives à l'âge adulte

Retentissement âge adulte
- **Fonction / Structurale**
- **Psycho-sociale**
- **Affectif (Grossesse)**

Nécessité d'une transition

EVOLUTION FONCTIONNELLE

n=268



	At Disease Onset	Within a Median of 14.9 yrs
Females	193 (72)	
Age, median yrs (range)	7.0 (0.3–15.3)	22.1 (13.2–31.1)
Disease duration, median yrs		14.9 (11.7–25.1)
Subtype		
Systemic	29 (11)	16 (6)
Pauciarticular	163 (61)	106 (40)
Polyarticular	76 (28)	146 (54)
Cumulative no. of affected joints, mean (SD)	5.4 (7.0)	10.6 (12.4)
Knee involvement	202 (75)	229 (85)
Ankle involvement	117 (43)	157 (58)
Finger joint involvement	55 (21)	121 (45)
Wrist involvement	64 (24)	105 (39)
Cervical involvement	24 (9)	73 (27)
Hip joint involvement	17 (6)	54 (20)
Predominantly symmetric arthritis	141 (53)	
ESR, mm/h, mean (SD)	37 (30)	11 (12)
Platelets, mean (SD)	392 (141)	264 (64)
Positive ANA	60 (22)	87 (32)
Positive IgM RF	12 (5)	13 (5)
Uveitis	33 (12)	50 (19)

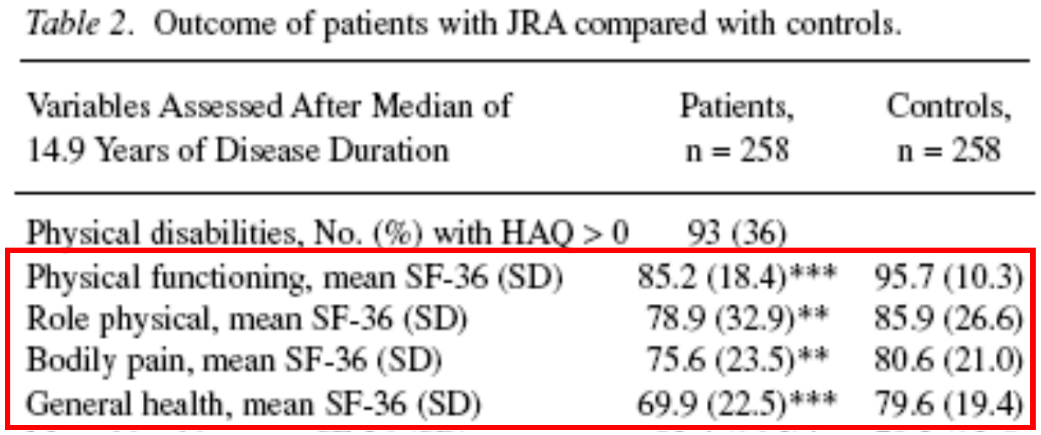


Table 2. Outcome of patients with JRA compared with controls.

Variables Assessed After Median of 14.9 Years of Disease Duration	Patients, n = 258	Controls, n = 258
Physical disabilities, No. (%) with HAQ > 0	93 (36)	
Physical functioning, mean SF-36 (SD)	85.2 (18.4)***	95.7 (10.3)
Role physical, mean SF-36 (SD)	78.9 (32.9)**	85.9 (26.6)
Bodily pain, mean SF-36 (SD)	75.6 (23.5)**	80.6 (21.0)
General health, mean SF-36 (SD)	69.9 (22.5)***	79.6 (19.4)

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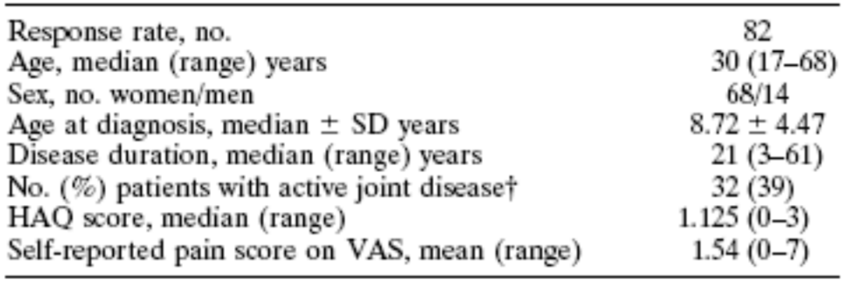
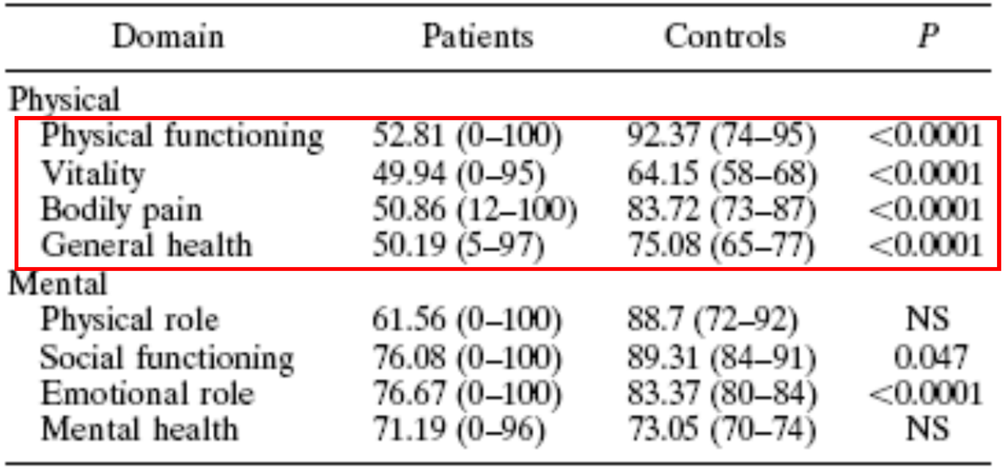
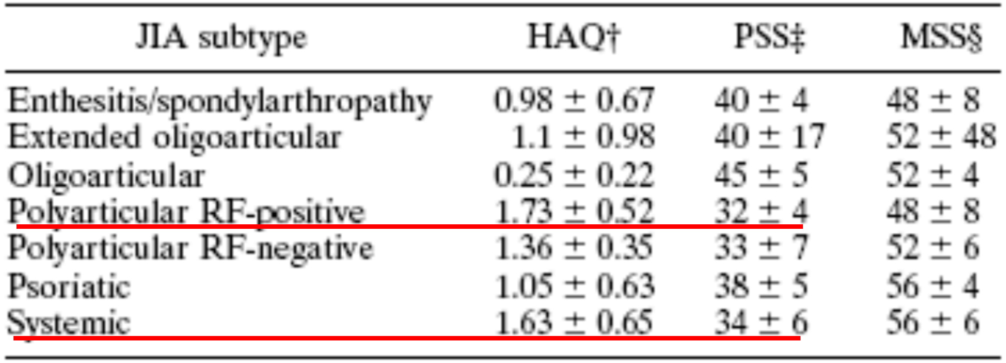
EVOLUTION FONCTIONNELLE



Response rate, no.	82
Age, median (range) years	30 (17–68)
Sex, no. women/men	68/14
Age at diagnosis, median ± SD years	8.72 ± 4.47
Disease duration, median (range) years	21 (3–61)
No. (%) patients with active joint disease†	32 (39)
HAQ score, median (range)	1.125 (0–3)
Self-reported pain score on VAS, mean (range)	1.54 (0–7)



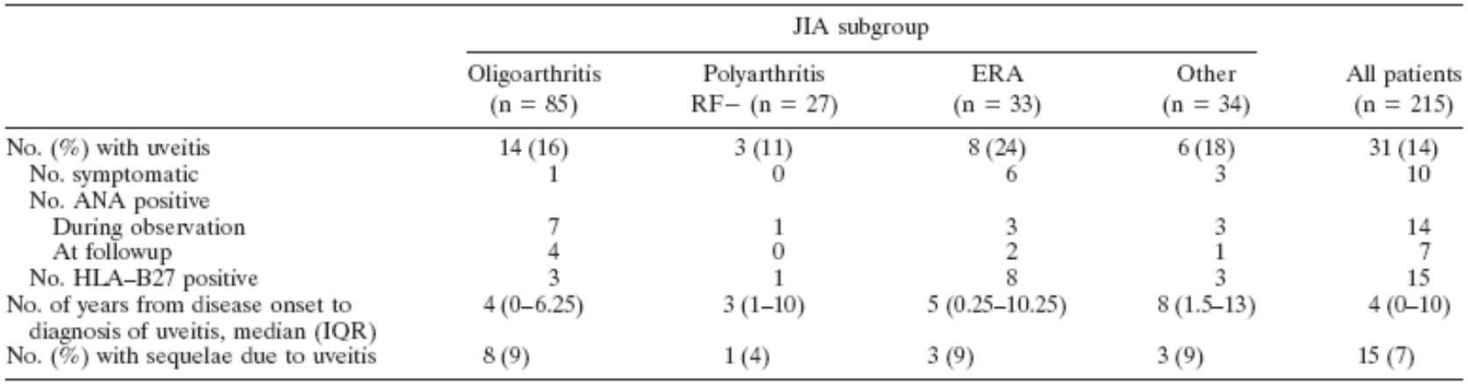
Domain	Patients	Controls	P
Physical			
Physical functioning	52.81 (0–100)	92.37 (74–95)	<0.0001
Vitality	49.94 (0–95)	64.15 (58–68)	<0.0001
Bodily pain	50.86 (12–100)	83.72 (73–87)	<0.0001
General health	50.19 (5–97)	75.08 (65–77)	<0.0001
Mental			
Physical role	61.56 (0–100)	88.7 (72–92)	NS
Social functioning	76.08 (0–100)	89.31 (84–91)	0.047
Emotional role	76.67 (0–100)	83.37 (80–84)	<0.0001
Mental health	71.19 (0–96)	73.05 (70–74)	NS



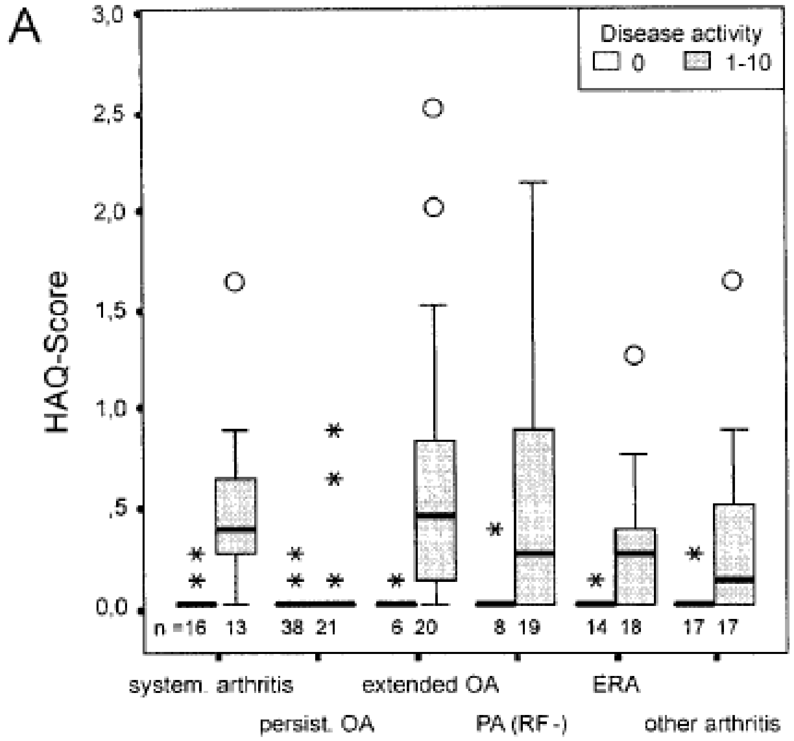
JIA subtype	HAQ†	PSS‡	MSS§
Enthesitis/spondylarthropathy	0.98 ± 0.67	40 ± 4	48 ± 8
Extended oligoarticular	1.1 ± 0.98	40 ± 17	52 ± 48
Oligoarticular	0.25 ± 0.22	45 ± 5	52 ± 4
Polyarticular RF-positive	1.73 ± 0.52	32 ± 4	48 ± 8
Polyarticular RF-negative	1.36 ± 0.35	33 ± 7	52 ± 6
Psoriatic	1.05 ± 0.63	38 ± 5	56 ± 4
Systemic	1.63 ± 0.65	34 ± 6	56 ± 6

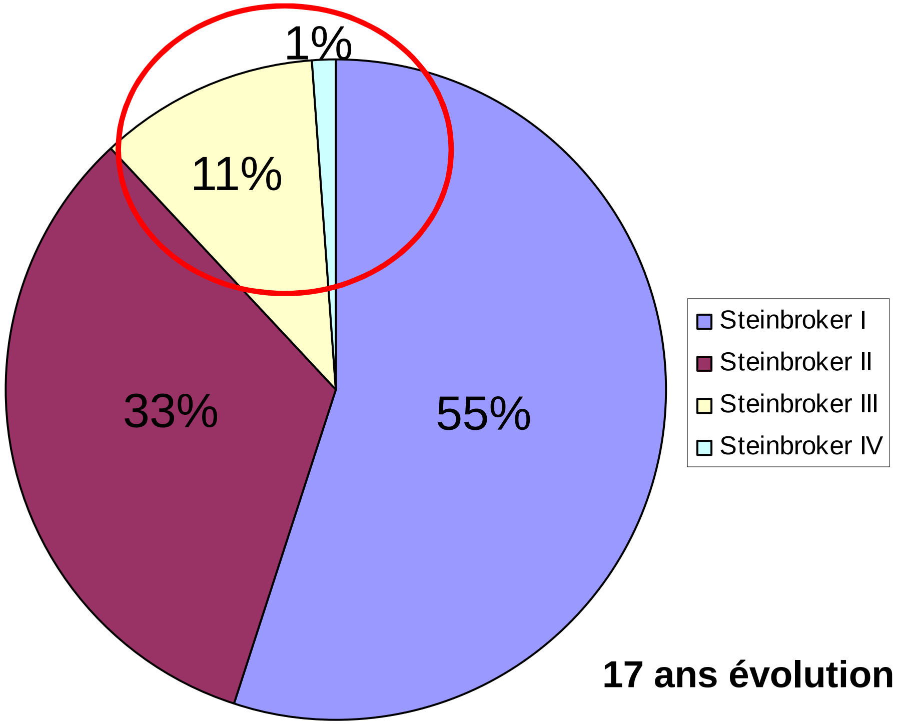
Foster et al. Arthritis Rheum 2002

EVOLUTION FONCTIONNELLE



	JIA subgroup				
	Oligoarthritis (n = 85)	Polyarthritis RF– (n = 27)	ERA (n = 33)	Other (n = 34)	All patients (n = 215)
No. (%) with uveitis	14 (16)	3 (11)	8 (24)	6 (18)	31 (14)
No. symptomatic	1	0	6	3	10
No. ANA positive					
During observation	7	1	3	3	14
At followup	4	0	2	1	7
No. HLA–B27 positive	3	1	8	3	15
No. of years from disease onset to diagnosis of uveitis, median (IQR)	4 (0–6.25)	3 (1–10)	5 (0.25–10.25)	8 (1.5–13)	4 (0–10)
No. (%) with sequelae due to uveitis	8 (9)	1 (4)	3 (9)	3 (9)	15 (7)

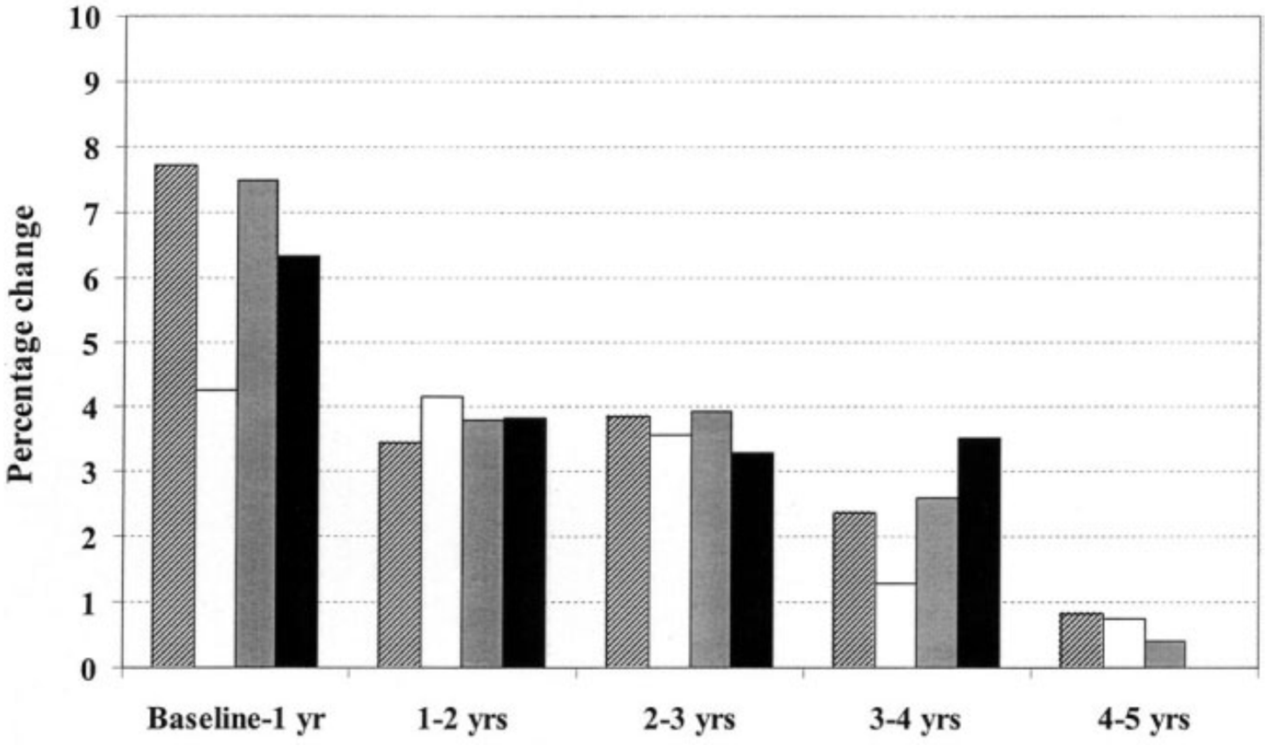




17 ans évolution

Minden et al. Arthritis Rheum 2002

EVOLUTION STRUCTURALE

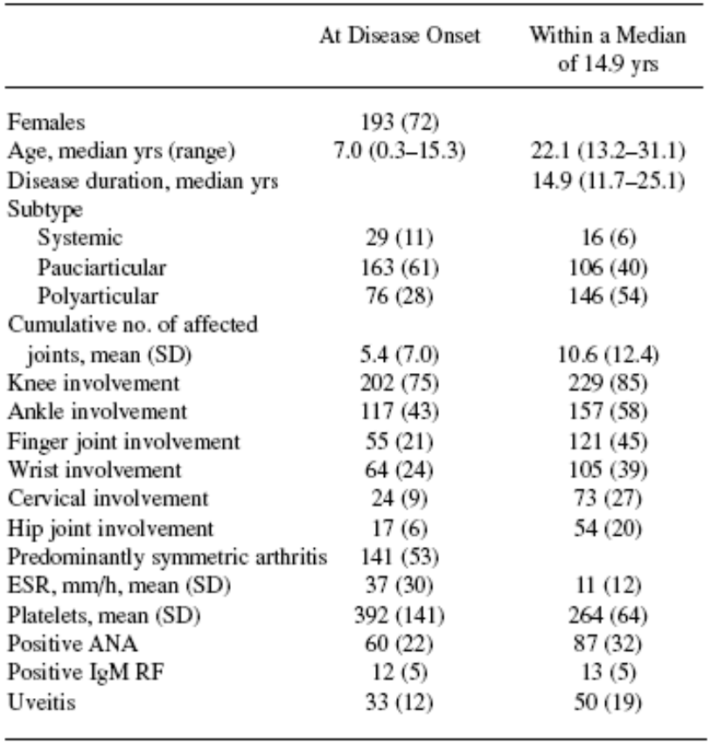


→ Fenêtre d'opportunité comme dans la PR de l'adulte

Ravelli et al. Arthritis Rheum 2006

EVOLUTION PSYCHOLOGIQUE

n=268



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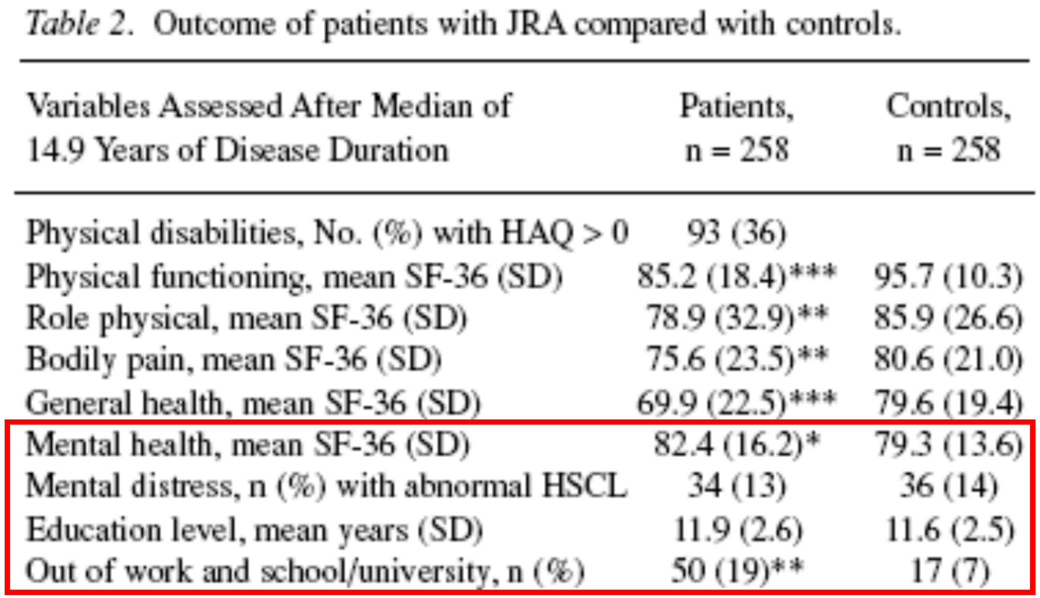

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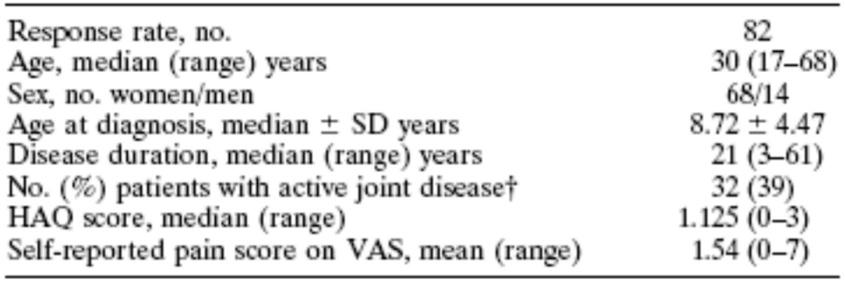
Mental health, mean SF-36 (SD)	82.4 (16.2)*	79.3 (13.6)
Mental distress, n (%) with abnormal HSCL	34 (13)	36 (14)
Education level, mean years (SD)	11.9 (2.6)	11.6 (2.5)
Out of work and school/university, n (%)	50 (19)**	17 (7)

Flato et al. J Rheumatol 2003

EVOLUTION PSYCHOLOGIQUE



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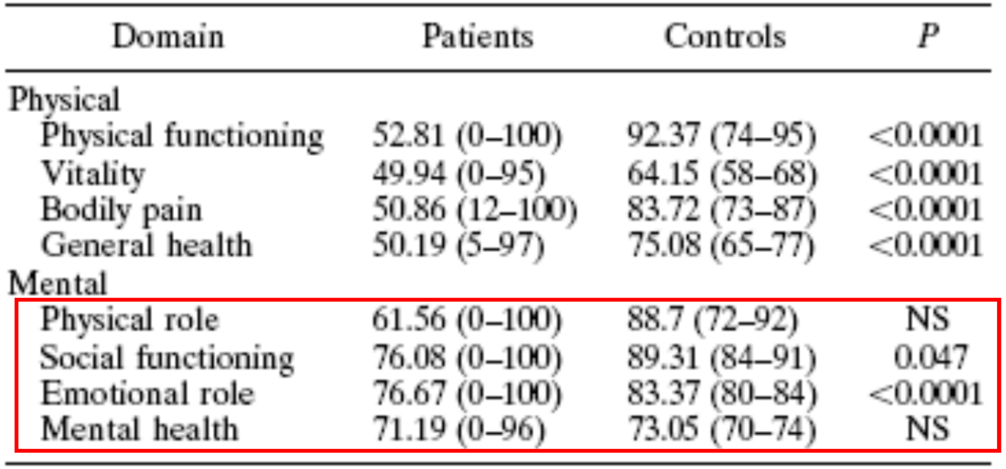

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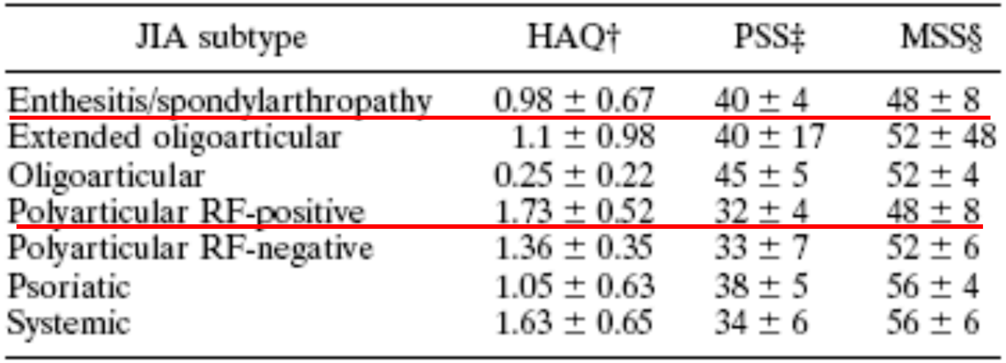

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Foster et al. Arthritis Rheum 2002

EVOLUTION SOCIETALE
Scolarité

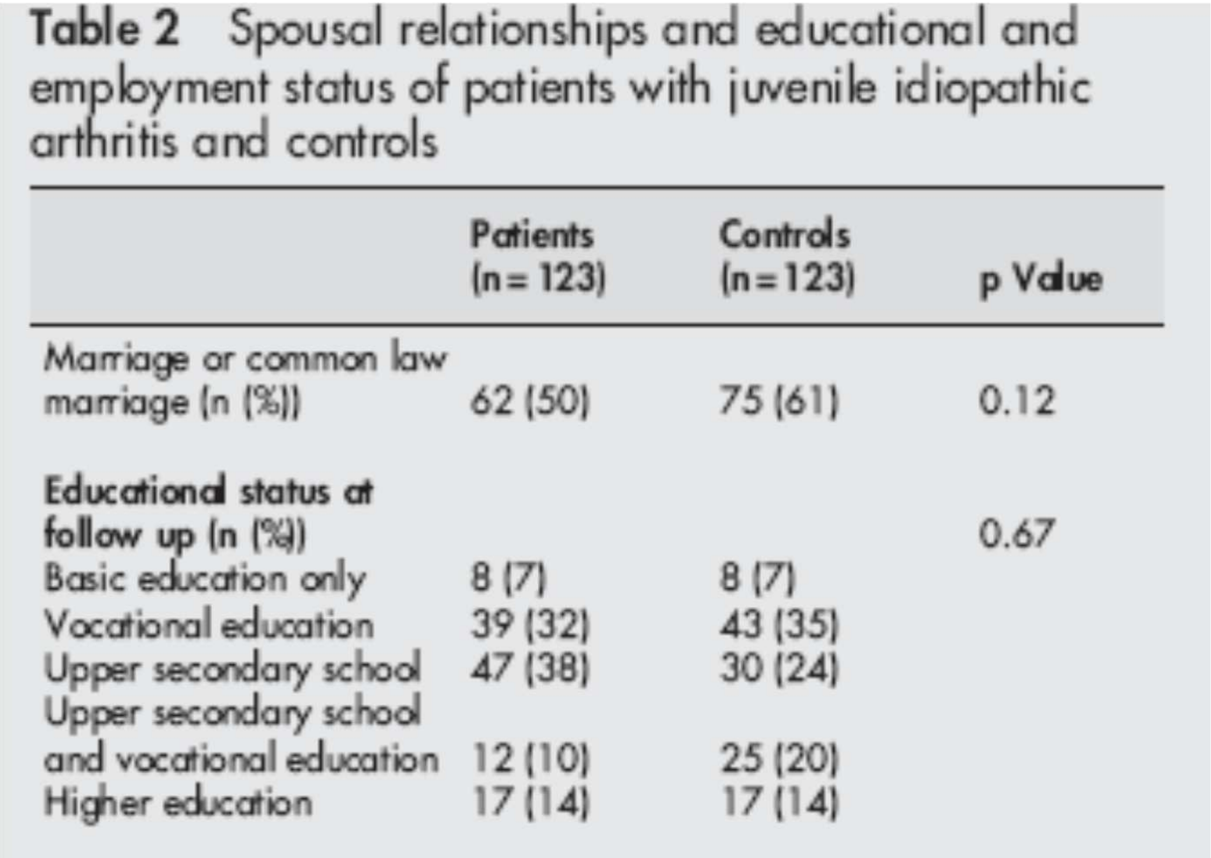


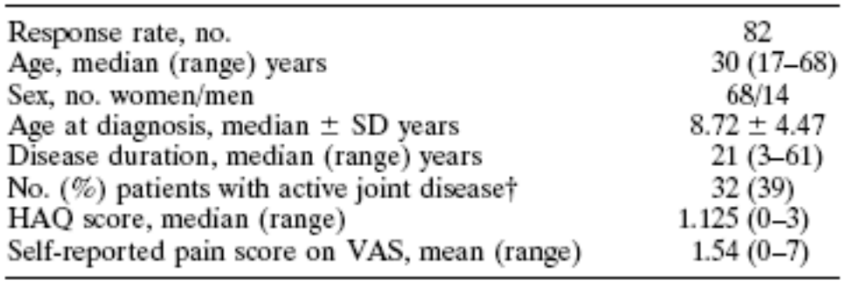
Table 2 Spousal relationships and educational and employment status of patients with juvenile idiopathic arthritis and controls

	Patients (n = 123)	Controls (n = 123)	p Value
Marriage or common law marriage (n (%))	62 (50)	75 (61)	0.12
Educational status at follow up (n (%))			0.67
Basic education only	8 (7)	8 (7)	
Vocational education	39 (32)	43 (35)	
Upper secondary school	47 (38)	30 (24)	
Upper secondary school and vocational education	12 (10)	25 (20)	
Higher education	17 (14)	17 (14)	

CE N'EST PAS AVEC DES MENSONGES ET DE VAINES PROMESSES QUE L'ON RÉUSSIT DANS LA VIE !
ANE
ENA
PHILIPPE TASTET

Arkela et al. ARD 2005

EVOLUTION SOCIETALE
Scolarité



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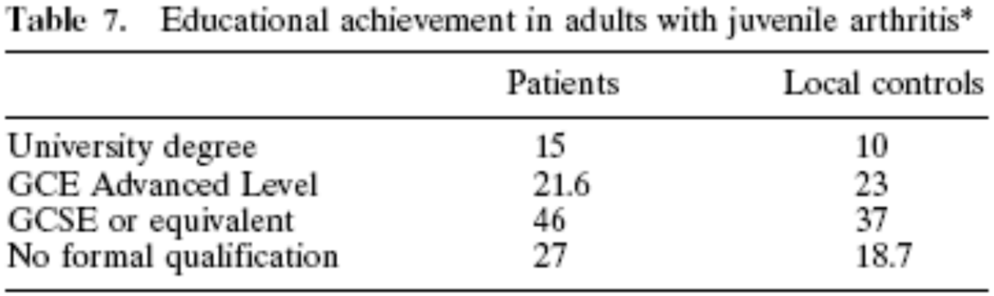


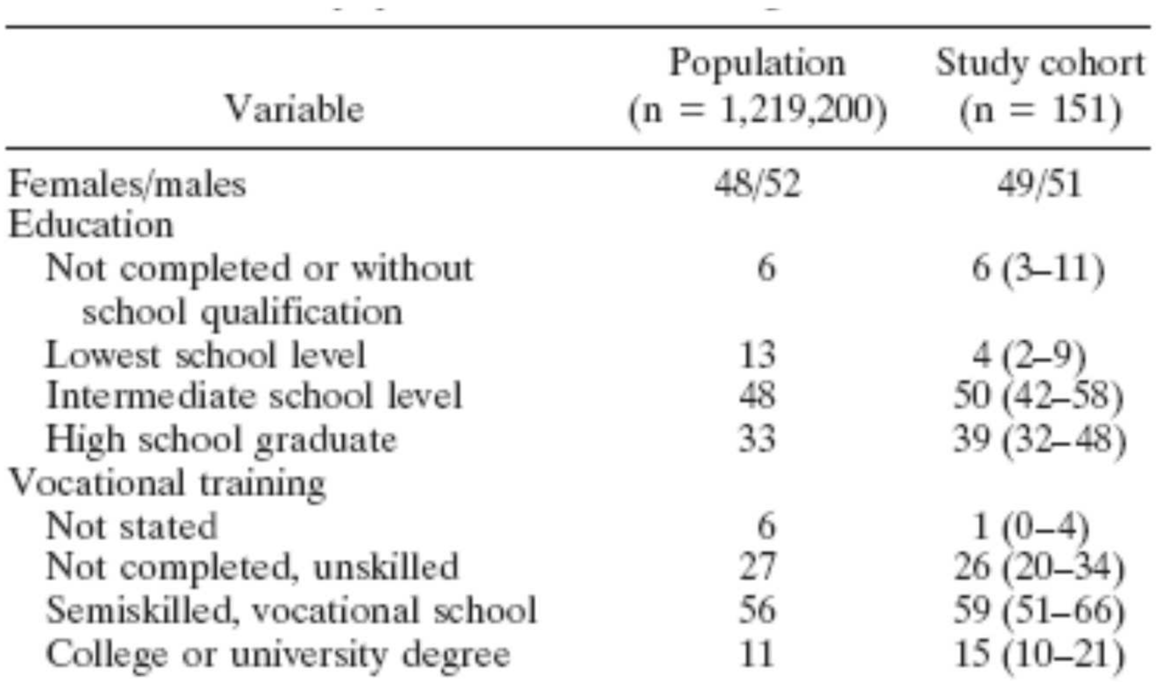
Table 7. Educational achievement in adults with juvenile arthritis*

	Patients	Local controls
University degree	15	10
GCE Advanced Level	21.6	23
GCSE or equivalent	46	37
No formal qualification	27	18.7

JIA semble faire de meilleures études

Foster et al. Arthritis Rheum 2002

EVOLUTION SOCIETALE
Scolarité



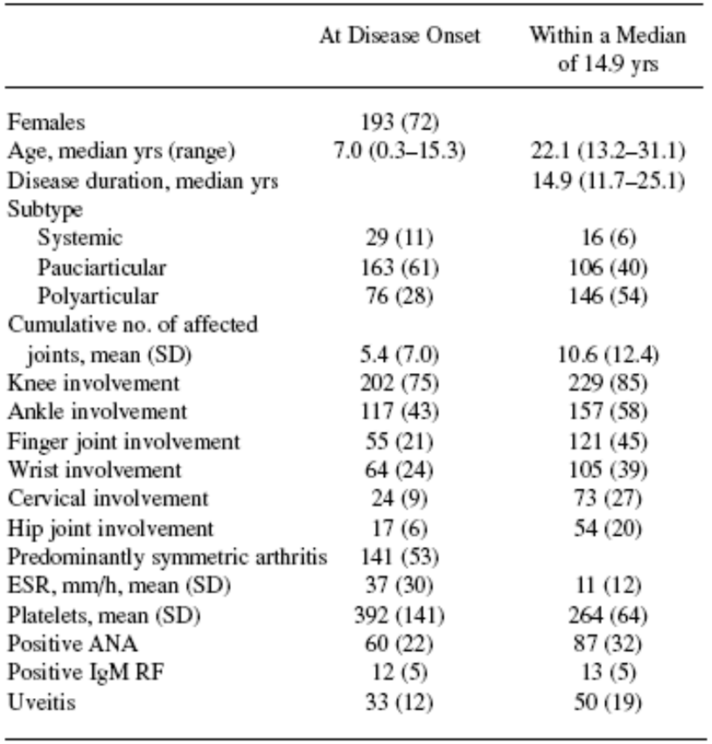
Variable	Population (n = 1,219,200)	Study cohort (n = 151)
Females/males	48/52	49/51
Education		
Not completed or without school qualification	6	6 (3–11)
Lowest school level	13	4 (2–9)
Intermediate school level	48	50 (42–58)
High school graduate	33	39 (32–48)
Vocational training		
Not stated	6	1 (0–4)
Not completed, unskilled	27	26 (20–34)
Semiskilled, vocational school	56	59 (51–66)
College or university degree	11	15 (10–21)

Tendance JIA > contrôles dans les études

Minden et al. Arthritis Rheum 2002

EVOLUTION SOCIETALE
Profession

n=268



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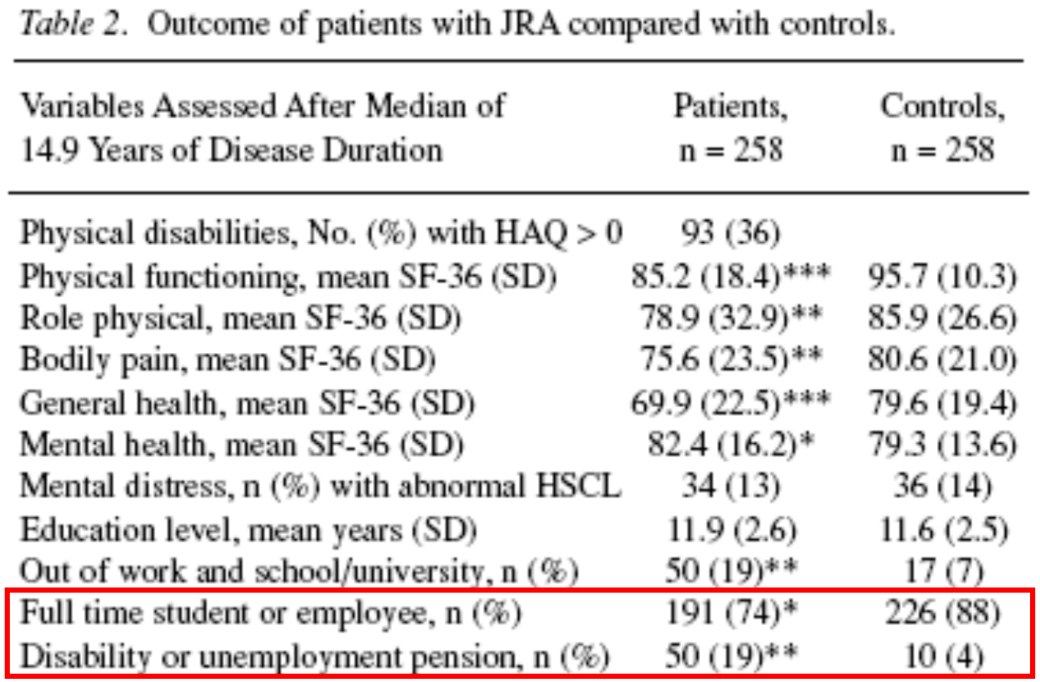

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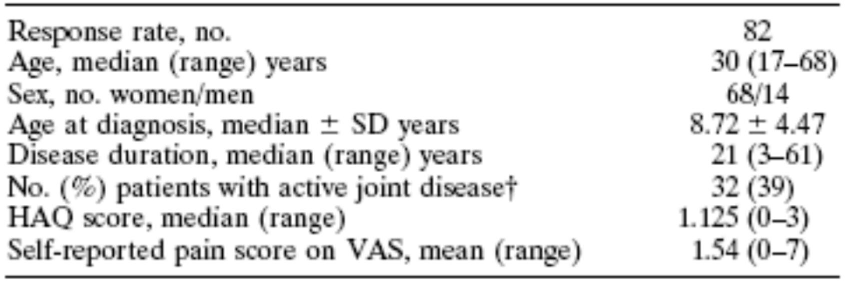
Out of work and school/university, n (%)	50 (19)**	17 (7)
Full time student or employee, n (%)	191 (74)*	226 (88)
Disability or unemployment pension, n (%)	50 (19)**	10 (4)

Flato et al. J Rheumatol 2003

EVOLUTION SOCIETALE
Profession



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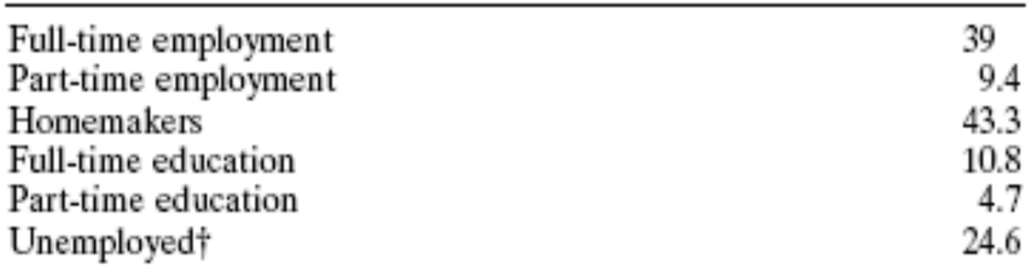


Full-time employment	39
Part-time employment	9.4
Homemakers	43.3
Full-time education	10.8
Part-time education	4.7
Unemployed†	24.6

Risque JIA X 3 / contrôles

Tendance :

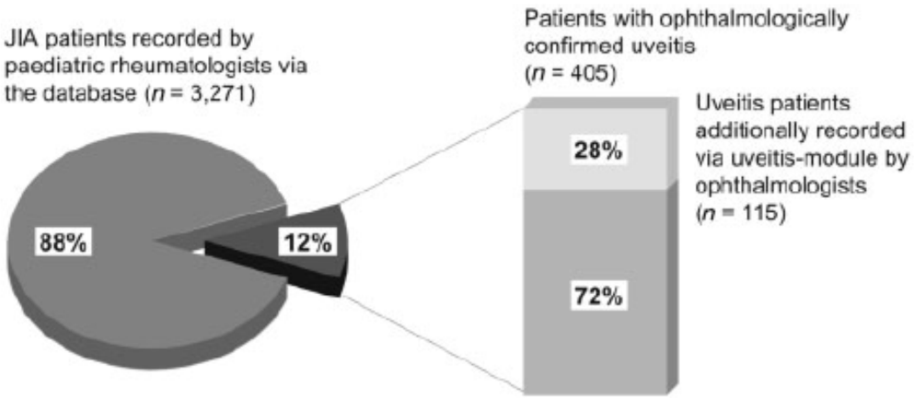
- **Mâle**
- **Poly FR+ / systémique**
- **HAQ élevés et SF36 bas**

Foster et al. Arthritis Rheum 2002

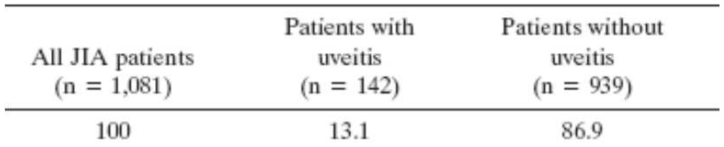
Uvéites et AJI

Prévalence

Allemagne (suivi 4 ans)

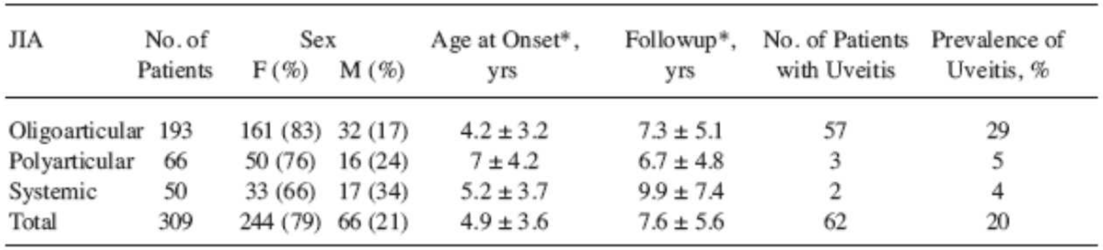


Canada (suivi 7 ans)



All JIA patients (n = 1,081)	Patients with uveitis (n = 142)	Patients without uveitis (n = 939)
100	13.1	86.9

Italie (suivi 7 ans)



JIA	No. of Patients	Sex F (%)	Sex M (%)	Age at Onset*, yrs	Followup*, yrs	No. of Patients with Uveitis	Prevalence of Uveitis, %
Oligoarticular	193	161 (83)	32 (17)	4.2 ± 3.2	7.3 ± 5.1	57	29
Polyarticular	66	50 (76)	16 (24)	7 ± 4.2	6.7 ± 4.8	3	5
Systemic	50	33 (66)	17 (34)	5.2 ± 3.7	9.9 ± 7.4	2	4
Total	309	244 (79)	66 (21)	4.9 ± 3.6	7.6 ± 5.6	62	20

➔ Prévalence entre 12 et 20%

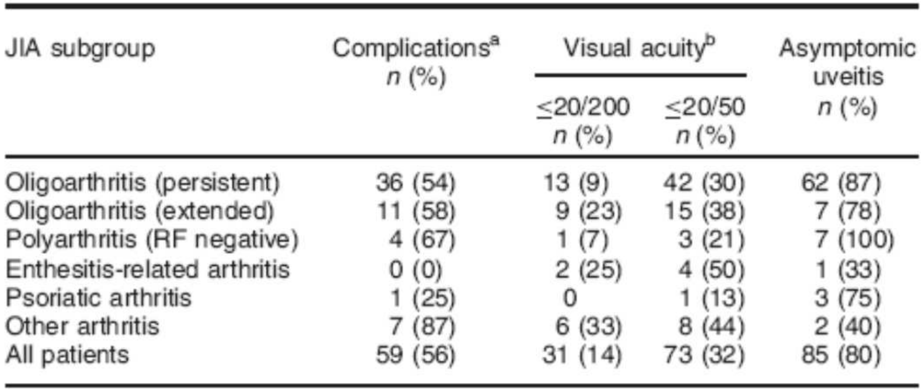
Uvéites et AJI

Type d'uvéites

- **Uvéite-AJI**
  - – Oligoarthrite, poly FR- (FAN+)
    - Uvéite à œil blanc
    - Indolore
    - Insidieuse +++

    ➔ Complications / traitements difficiles
  - – ERA
    - Uvéite à œil rouge
    - Douleurs +++
    - Aiguë

    ➔ Peu de complications / traitements efficaces

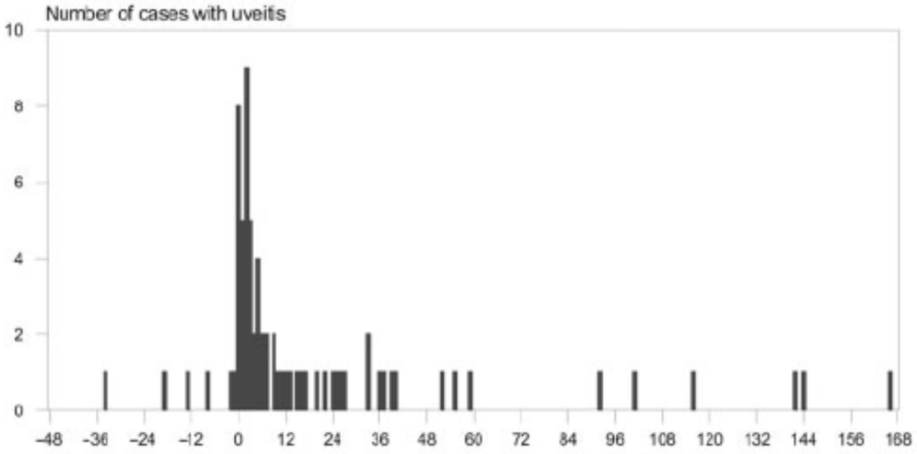


JIA subgroup	Complications[a] *n* (%)	Visual acuity[b]		Asymptomatic uveitis *n* (%)
		≤20/200 *n* (%)	≤20/50 *n* (%)	
Oligoarthritis (persistent)	36 (54)	13 (9)	42 (30)	62 (87)
Oligoarthritis (extended)	11 (58)	9 (23)	15 (38)	7 (78)
Polyarthritis (RF negative)	4 (67)	1 (7)	3 (21)	7 (100)
Enthesitis-related arthritis	0 (0)	2 (25)	4 (50)	1 (33)
Psoriatic arthritis	1 (25)	0	1 (13)	3 (75)
Other arthritis	7 (87)	6 (33)	8 (44)	2 (40)
All patients	59 (56)	31 (14)	73 (32)	85 (80)

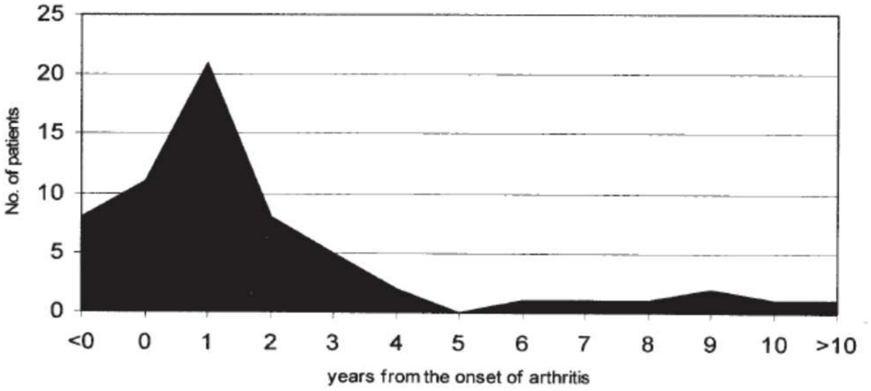
Uvéites et AJI

Evolution uvéites

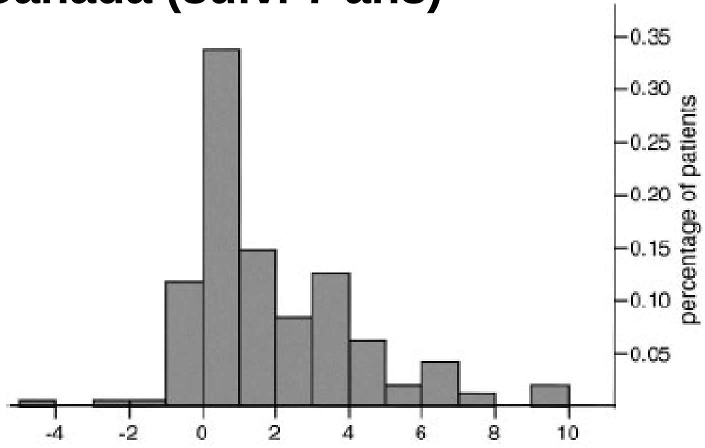
Allemagne (suivi 4 ans)



Italie (suivi 7 ans)



Canada (suivi 7 ans)



Uvéites et AJI

Evolution uvéites

- **Uvéite-AJI**
  - Apparition dans les 5 premières années d'évolution
  - Suivi précoce et rapprochée

Oligoarthrite et polyarthrite FR- surtout si AAN+ (et SpA)
- Cs ophtalmologique OBLIGATOIRE / 3mois pour 4 ans
- puis cs / 6 mois pour (3 ans)
- puis cs /an (comme population générale)

Vaccins et AJI

- **Vaccins / toxines-antigéniques**
  - A priori même immunogénicité *in vitro*
  - Pas de poussée de la maladie ➔ être en rémission
  - Pas de données sur l'induction de JIA
  - Par définition pas de maladie infectieuse induite

➔ **Aucune contre-indication, au contraire...**

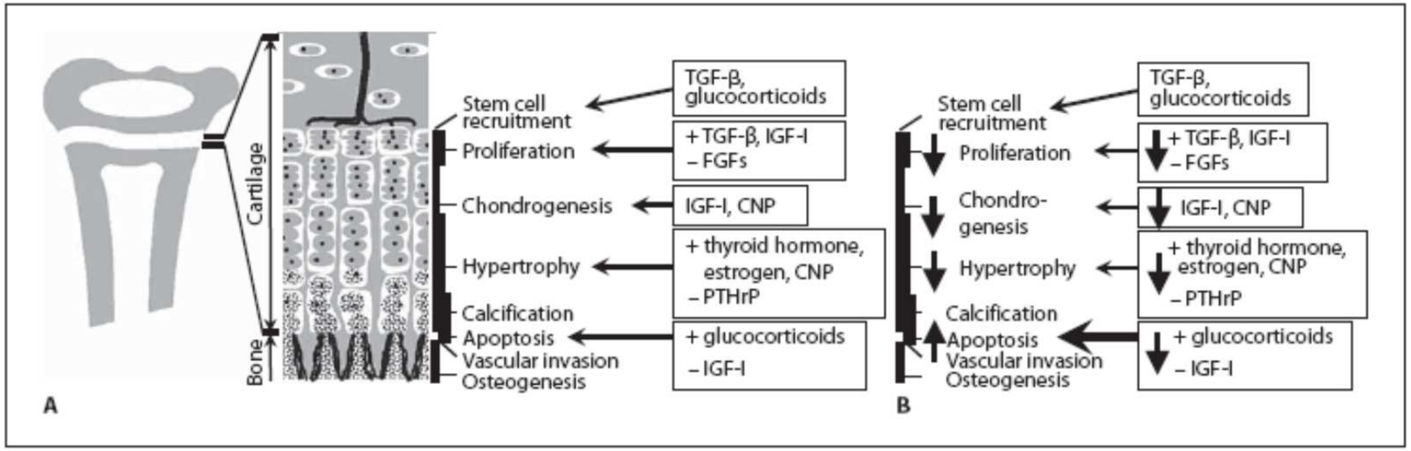
Vaccins et AJI

- **Vaccins vivants atténués**
  - A priori même immunogénicité *in vitro*
  - Pas de poussée de la maladie ➔ être en rémission+++
  - Pas de données sur l’induction de JIA
  - Pas de maladie induite dans les études

➔ Discussion au cas par cas...

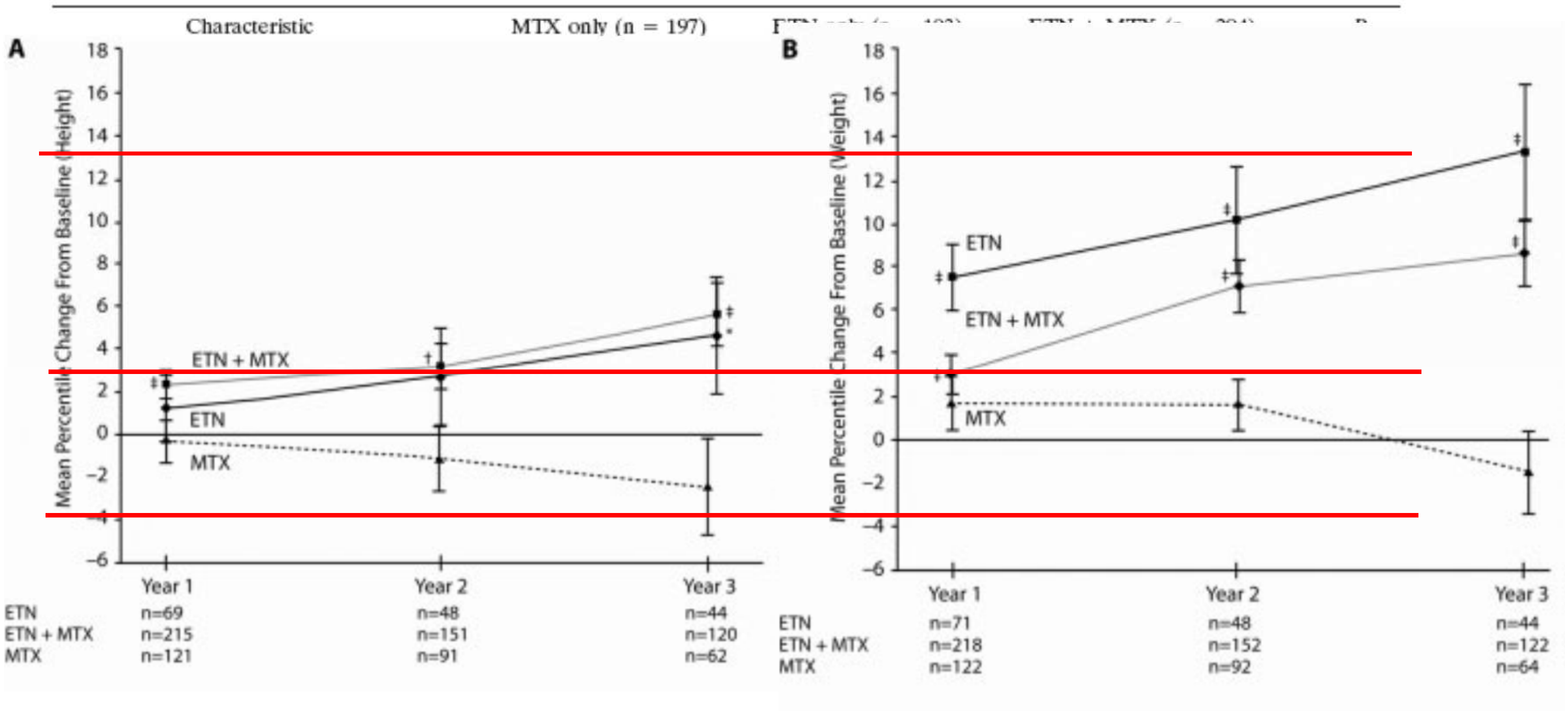
Croissance et AJI

- Générale
  - – Rôle de l'inflammation
    - IL-6 et IGF1
  - – Rôle des traitements = Corticoïdes +++


Cartilage
Bone
Stem cell recruitment
Proliferation
Chondrogenesis
Hypertrophy
Calcification
Apoptosis
Vascular invasion
Osteogenesis
TGF-β, glucocorticoids
+ TGF-β, IGF-I
– FGFs
IGF-I, CNP
+ thyroid hormone, estrogen, CNP
– PTHrP
+ glucocorticoids
– IGF-I
A
Stem cell recruitment
Proliferation
Chondro-genesis
Hypertrophy
Calcification
Apoptosis
Vascular invasion
Osteogenesis
TGF-β, glucocorticoids
+ TGF-β, IGF-I
– FGFs
IGF-I, CNP
+ thyroid hormone, estrogen, CNP
– PTHrP
+ glucocorticoids
– IGF-I
B

Croissance et AJI

- **Générale**
  - **Evolution à l'âge adulte ➔ rôle des traitements**



Giannini et al. Arthritis Rheum 2002

Croissance et AJI

- **Générale**
  - **Evolution à l'âge adulte ➔ rôle des traitements**

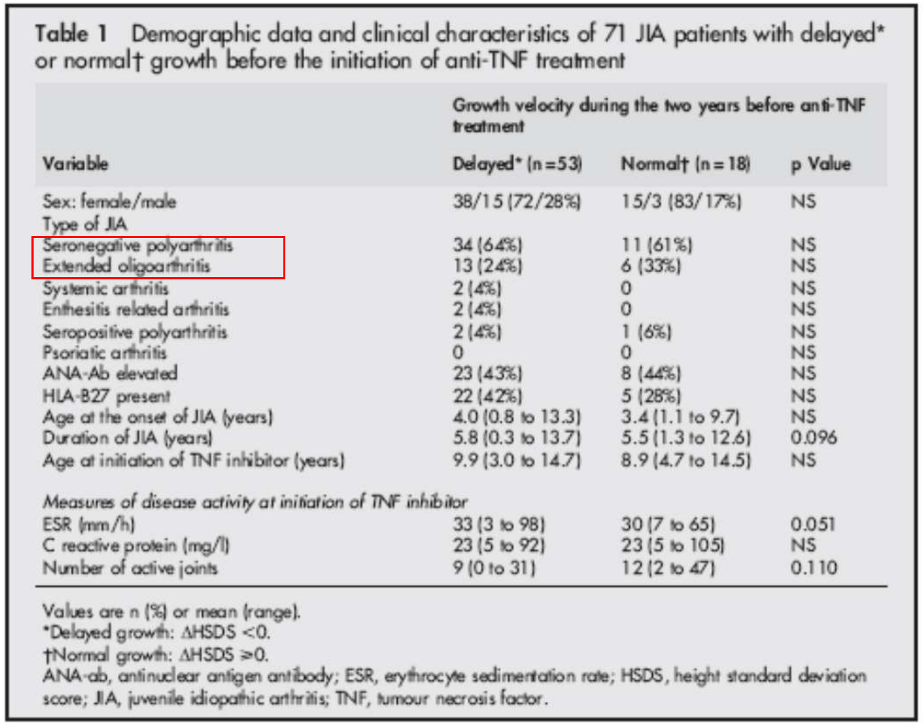
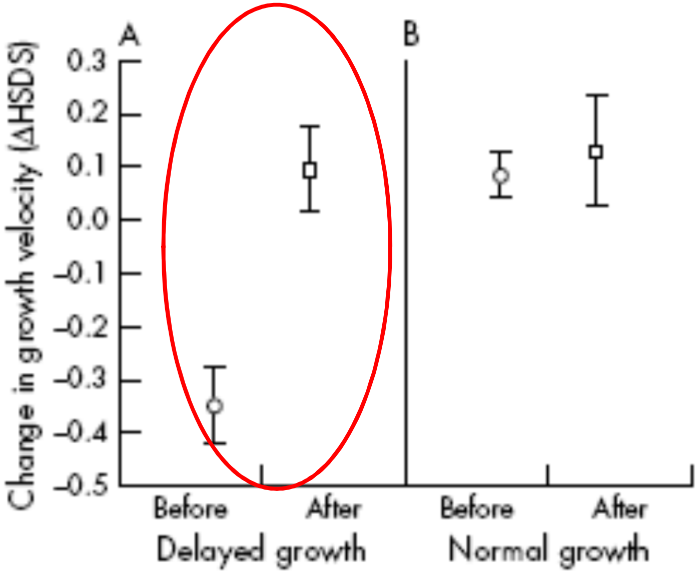


Table 1 Demographic data and clinical characteristics of 71 JIA patients with delayed* or normal† growth before the initiation of anti-TNF treatment

Variable	Growth velocity during the two years before anti-TNF treatment		
	Delayed* (n = 53)	Normal† (n = 18)	p Value
Sex: female/male	38/15 (72/28%)	15/3 (83/17%)	NS
Type of JIA			
Seronegative polyarthritis	34 (64%)	11 (61%)	NS
Extended oligoarthritis	13 (24%)	6 (33%)	NS
Systemic arthritis	2 (4%)	0	NS
Enthesitis related arthritis	2 (4%)	0	NS
Seropositive polyarthritis	2 (4%)	1 (6%)	NS
Psoriatic arthritis	0	0	NS
ANA-Ab elevated	23 (43%)	8 (44%)	NS
HLA-B27 present	22 (42%)	5 (28%)	NS
Age at the onset of JIA (years)	4.0 (0.8 to 13.3)	3.4 (1.1 to 9.7)	NS
Duration of JIA (years)	5.8 (0.3 to 13.7)	5.5 (1.3 to 12.6)	0.096
Age at initiation of TNF inhibitor (years)	9.9 (3.0 to 14.7)	8.9 (4.7 to 14.5)	NS
Measures of disease activity at initiation of TNF inhibitor			
ESR (mm/h)	33 (3 to 98)	30 (7 to 65)	0.051
C reactive protein (mg/l)	23 (5 to 92)	23 (5 to 105)	NS
Number of active joints	9 (0 to 31)	12 (2 to 47)	0.110

Values are n (%) or mean (range).
*Delayed growth: ΔHSDS <0.
†Normal growth: ΔHSDS ≥0.
ANA-ab, antinuclear antigen antibody; ESR, erythrocyte sedimentation rate; HSDS, height standard deviation score; JIA, juvenile idiopathic arthritis; TNF, tumour necrosis factor.



2 ans

Anti-TNF = ETN ou Infliximab

Tyndjala et al. ARD 2006

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

Kourir

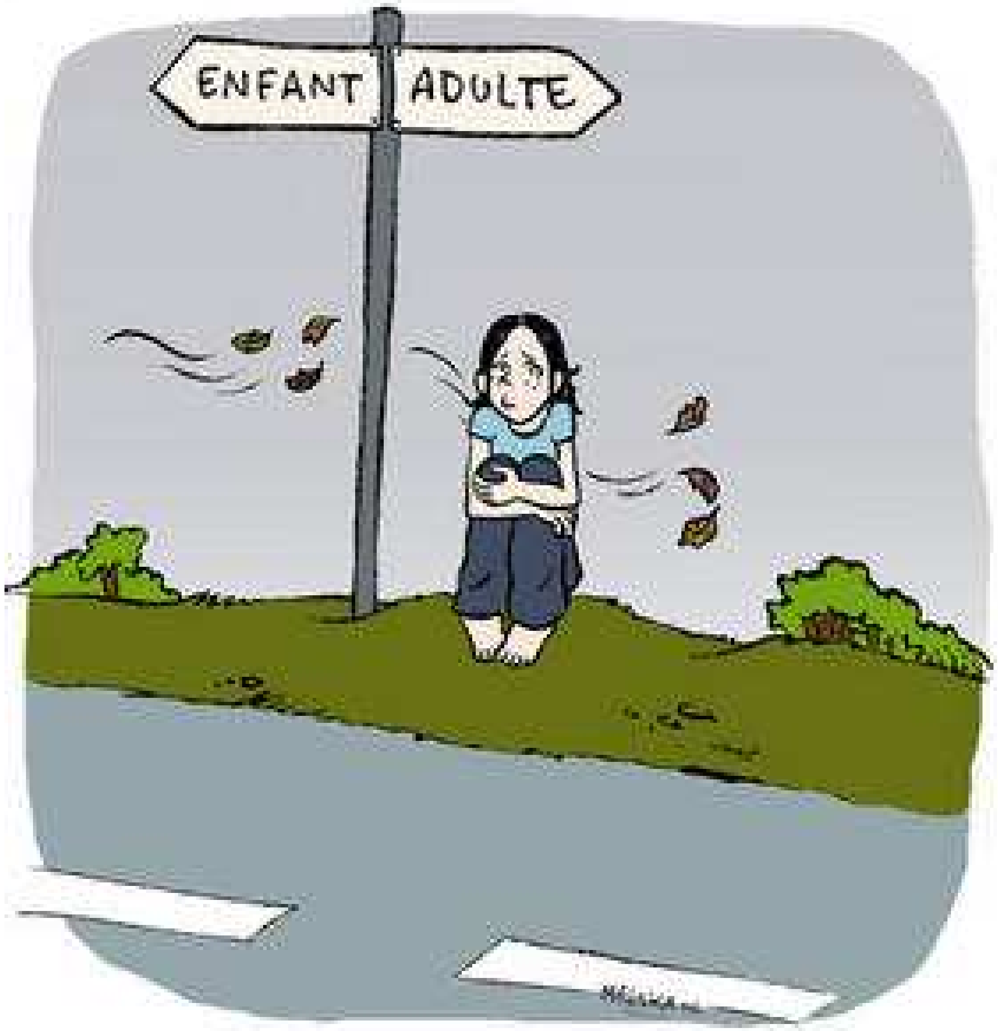
TRANSITION RHUMATOLOGIE PEDIATRIQUE-ADULTE

Dr WIPFF Julien, Dr DESLANDRE Chantal

Service de Rhumatologie A, Hôpital Cochin, Centre de référence des AJI (Necker)

RhumPed

Centre National de références Arthrites juvéniles


ENFANT
ADULTE

TRANSITION ≠ TRANSFERT

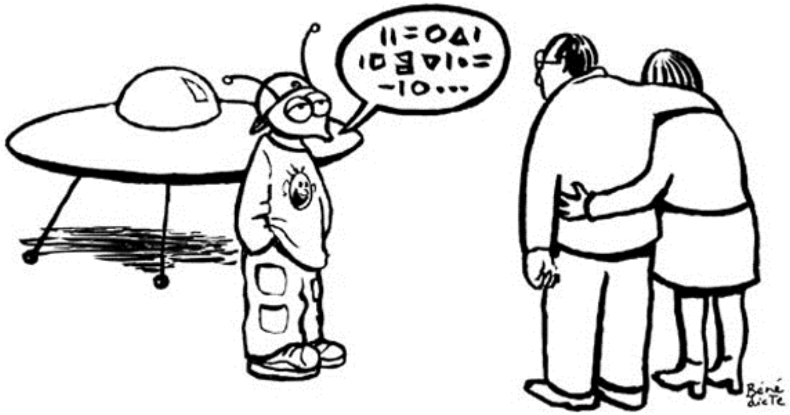
- **L’AJI a un important retentissement sur :**
    - l’état psychologique et relationnel,

© Jean-Luc Bodin/Picture Tank

TRANSITION ≠ TRANSFERT

- **L’AJI a un important retentissement sur :**
  - l’état psychologique et relationnel,

© Jean-Luc Bertini/Picture Tank



TRANSITION ≠ TRANSFERT

- **L’AJI a un important retentissement sur :**

  - l’état psychologique et relationnel,
  - le travail scolaire,

TRANSITION ≠ TRANSFERT

- **L’AJI a un important retentissement sur :**
  - l’état psychologique et relationnel,
  - le travail scolaire,
  - les activités quotidiennes à la maison.

La petite page de Gloria
Halte aux rides d'expression!
Bon.
Allez.
OK.
MMK

par Marianne Maury Kaufmann

Les besoins

- Etude : méthode Delphi
  - Amélioration d'emblée
    - PEC extra-médicale, psycho-sociale
    - Individualisée
    - Centrée sur l'adolescent
    - Adolescent vu seul
    - Continuité des soins
  - Amélioration ultérieure
    - Multidisciplinaire
    - Lieu adapté
    - Rencontrer d'autres adolescents comme eux

Shaw KL. Rheumatology 2004

La réponse

programme de transition

- Référent transition +++ (centralisation)

- Objectifs ? ➔ adaptés aux besoins
- Moyens ?
- Âge ?
- Efficacité ?

Moyens

- **Nécessité d’un lien étroit avec le service pédiatrique permettant**

- **Nécessité d’un intérêt particulier du personnel médical et paramédical dans la prise en charge des jeunes adultes.**

Moyens

Prise en charge globale = plusieurs domaines
Un référent médical

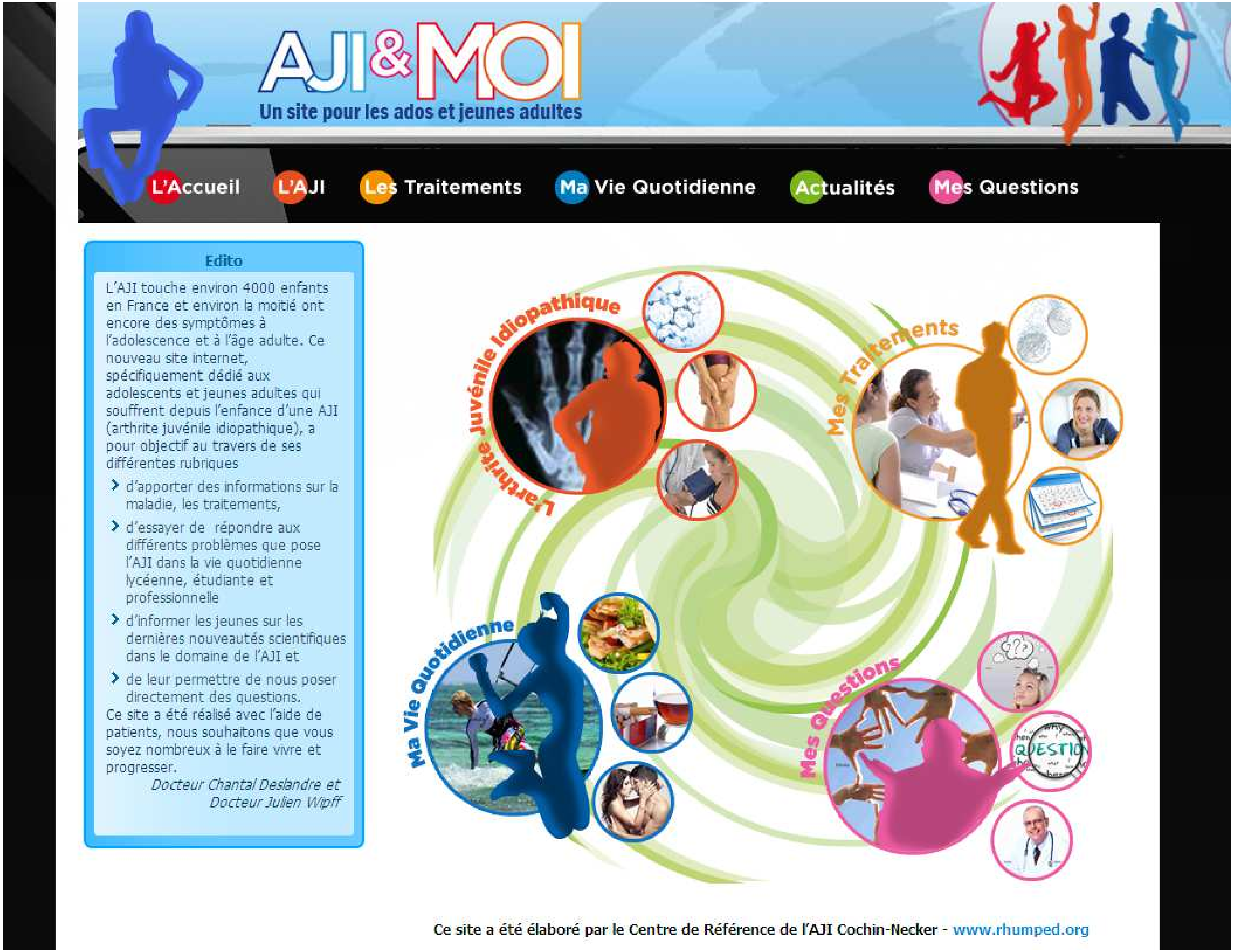
- **Médicale**
  - Maladie [orale, écrite, internet (sites médicaux, associations, forum...)]

  ➔ ajietmoi.fr

  - Traitements

  - Cs suffisamment longue (temps X 2)
  - Cs seule avec l'adolescent progressive - autonomie
  - Cs avec l'équipe adulte « en pont » ou commune

  ➔ Consultation dédiée aux jeunes adultes


AJI&MOI
Un site pour les ados et jeunes adultes
L'Accueil
L'AJI
Les Traitements
Ma Vie Quotidienne
Actualités
Mes Questions
L'arthrite Juvénile Idiopathique
Mes Traitements
Ma Vie Quotidienne
Mes Questions

Edito

L'AJI touche environ 4000 enfants en France et environ la moitié ont encore des symptômes à l'adolescence et à l'âge adulte. Ce nouveau site internet, spécifiquement dédié aux adolescents et jeunes adultes qui souffrent depuis l'enfance d'une AJI (arthrite juvénile idiopathique), a pour objectif au travers de ses différentes rubriques

- d'apporter des informations sur la maladie, les traitements,
- d'essayer de répondre aux différents problèmes que pose l'AJI dans la vie quotidienne lycéenne, étudiante et professionnelle
- d'informer les jeunes sur les dernières nouveautés scientifiques dans le domaine de l'AJI et
- de leur permettre de nous poser directement des questions.

Ce site a été réalisé avec l'aide de patients, nous souhaitons que vous soyez nombreux à le faire vivre et progresser.

Docteur Chantal Deslandre et
Docteur Julien Wipff

Ce site a été élaboré par le Centre de Référence de l'AJI Cochin-Necker - www.rhumped.org

Moyens

Prise en charge globale = plusieurs domaines

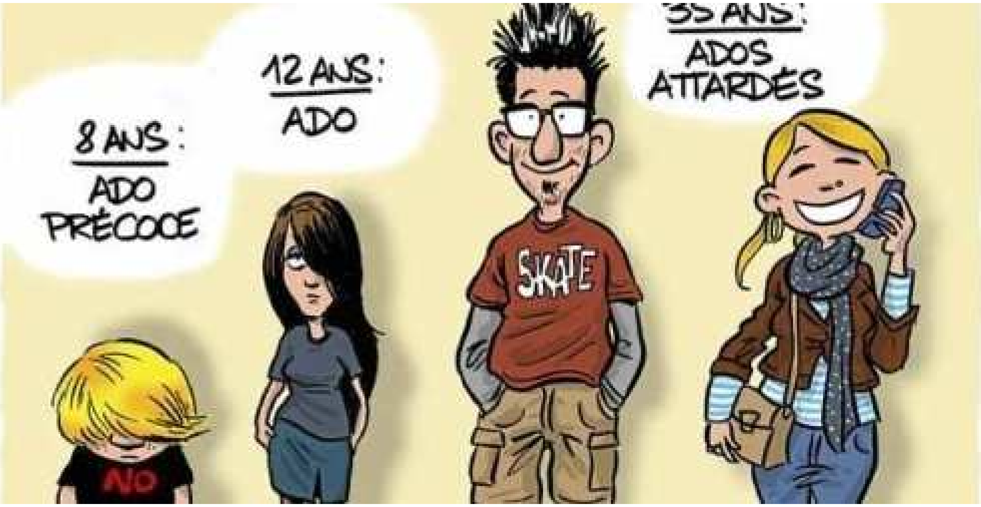
Un référent médical

- **Psychosociale**
  - Attitude du médecin active nécessaire
  - HEADSS
    - » H = Home
    - » E = Education / Exercise
    - » A = Activities / Affect
    - » D = Drugs / Diet
    - » S = Sexuality
    - » S = Sleep
  - Professionnels +++

Âge

- **Flexibilité +++**

- **11-14 ans ?????**
  - En parler avant surtout


8 ANS :
ADO PRÉCOCE
NO
12 ANS :
ADO
SKATE
35 ANS :
ADOS ATTARDÉS

TRANSITION – Spécificité

- **Difficultés inhérentes à la transition ?**
  - Rupture de suivi
    - Longue durée de la maladie
    - Adolescents
    - Etudes
    - Prise en charge (Sécurité sociale)
    - Changement de médecin

⇒ Insister +++ mais savoir parfois laisser du lest
⇒ Expliquer +++
⇒ Ne pas interdire systématiquement
⇒ Aide aux démarches (certificats …)

TRANSITION – Spécificité

- **Difficultés inhérentes à la transition ?**
  - Sexualité
    - Tabou
    - Retentissement AJI sur développement
    - Confiance médecin-patient(e)
    - Sans les parents

    ⇒ Contraception

    ⇒ MST

    - NB : même status marital = même activité sexuelle

  - Descendance
    - Pas de baisse de la fécondité

TRANSITION

- Conclusion

  - Spécificité des AJI avec évolution chronique
  - Spécificité des adolescents
  - Evolution selon la pathologie
  - Autonomisation

  - Prise en charge spécialisée multidisciplinaire

MERCI POUR VOTRE ATTENTION

Consultation de transition de Cochin

Dr J Wipff, Pr C Miceli-Richard

Tous les vendredis

AJI&MOI
Un site pour les ados et jeunes adultes
L'Accueil
L'AJI
Les Traitements
Ma Vie Quotidienne
Actualités
Mes Questions