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## Transition of the patient with Childhood-onset SLE

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### ABSTRACT

This review aims to depict the profile of the childhood onset-SLE (c-SLE) and the related challenges that need to be managed in order to achieve an uneventful programmed transition from the family-oriented Pediatric Rheumatology Outpatient Clinic to the adult patient-focused one. Transition is a dynamic, continuous and interactive process where a triad is involved: the medical staff, the pediatric patient and the family. Their mutual collaboration and interaction start at the announcement of the diagnosis and is continuously supported by the ongoing multi-dimensional patient's and family's education. A prerequisite of a successful transition is the stepwise consciousness of c-SLE

*per se* as well as the development of essential skills for the management of medical, psychosocial and educational/professional consequences derived during the course of the disease. The ideal time point of the final phase of transition (moving to adults' care) requires disease remission and the patient's confirmed dexterity for life self-management and coping with his/her difficult and unpredictable chronic disease.

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### 1. THE PORTRAIT OF PEDIATRIC SLE

Pediatric systemic lupus erythematosus (SLE) or Childhood onset SLE (pSLE) - or as previously termed, juvenile SLE (juvenile SLE) - is SLE with an onset prior to the patient's 18<sup>th</sup> birthday.<sup>1</sup>

The disease commencement and course have a greater load as compared to adult SLE. More specifically, pSLE has a more aggressive onset, and predominant initial involvement of systems and organs differ; with a greater likelihood of any organ involvement, and not only the kidneys or the CNS. Thus, a prompt diagnosis aiming to the early and aggressive disease interception is crucial, in order to prevent the damage development in a still growing organism.<sup>2-6</sup>

### 2. CHALLENGES FOR THE ADOLESCENT FROM THE TIME OF PSLE DIAGNOSIS UNTIL THE TRANSITION TO THE ADULT CLINIC

The disease impact on an individual and family base is summarized in **Table 1**.<sup>7</sup> These consequences derive from both the disease *per se* and the effects of the therapeutic options. The adolescent is asked to give his/her consent, following his/her information about treatment choices, suggested therapeutic changes and the impact of potential drug-induced adverse events; as for example, from administration of steroids, immune-suppressants or even agents, still "off-label" for pediatric patients. As pSLE is typically diagnosed in adolescence, the period for acceptance, self-education and self-management preparation in respect to the disease, is shorter than in Juvenile Idiopathic Arthritis.<sup>7</sup> Thus, the stepwise transition process needs to be more intense.

### 3. CHARACTERISTICS OF THE ADOLESCENTS WITH PSLE THAT THE HEALTH CARE PROVIDERS INVOLVED IN THE TRANSITION NEED TO KNOW ABOUT

Patients with pSLE can remain under the care of a

pediatric Rheumatologist until chronological adulthood, according to his/her will.<sup>10</sup> However, during the follow-up period, he/she will be prepared for the gradual "weaning" from the "physician-family" umbrella, to become independent and develop trustful relations with the health professionals of both Clinics.

The psychosocial maturity, though, may not progress in parallel to chronological age in several patients with chronic diseases, as in pSLE.<sup>10-13</sup> Additionally, unpredictable changes of the residence due to educational or working conditions may require an unscheduled switch of the adolescent with pSLE to another medical team or family physician. Lastly, at this critical period, when the pSLE patient is challenged to get acquainted with another physician of his/her confidence, several factors may interfere with this effort: the creation of sexual relationships, the restrictions regarding appropriate methods of contraception for pSLE patients, as well as possible pregnancies. All these factors make the young patient's effort to balance between life and the requirements of his/her disease very difficult (**Table 2**).

### 4. The process of transition from the pediatric to the adult Rheumatologist

Regardless of the transition model chosen by the relevant medical team, there are certain predefined targets, which, if achieved, predict a successful integration into the new adult-oriented medical setting.

#### Education on the self-management of pSLE

The gradual, planned multi-dimensional patient and family education on the disease characteristics and management is individualized: it progresses according to the pace imposed by the family. It aims to develop the patient's skills in respect to coping with the medical, psychosocial, educational or professional consequences emerging during the disease course.

**Table 1.** Impact of pediatric SLE on the patient and the family

#### 1. Impact on the patients

Physical or mental symptoms derived either from the chronic disease or the treatment or the damage development:

- Bad mood or even body image rejection
- Frequent school absences due to disease activity or follow-up visits leading to impaired academic performance
- Absence from sports, extracurricular activities or peer gatherings due to disease activity or physical disability. They may result in reduced or disturbed sociability

#### 2. Impact on the family members

- Shrinking of personal time, changes in the conditions of family life or work due to:
  - a. Continuous follow-up visits or hospital admissions, scheduled or unscheduled
  - b. Direct or indirect involvement in the delivery or administration of pSLE treatment
  - c. Continuous stress, deranged family dynamics, financial consequences

**Table 2.** Issues for discussion and solution during the transition process

Items that deserve clarification	Discussion domains
Physical activity and sports	Sun-protected and stress-free outdoor activities
Knowledge of the pSLE disease, acceptance of the diagnosis	During each visit, delivery of contemporary disease related-information and consent provision for each required intervention
Residence: Family dynamics	Residence and way of living including the preferred surrounding
Inter-personal relations-sexual life	Comradeship, contraception, pregnancy/parenthood under surveillance, sexually transmitted diseases, health-related updated information from reliable sources
Body image: Specific diets	Body type, dietary habits, pSLE impact on body shaping and somatic functions
Academic performance: vocational orientation/work	Daily academic schedule, Future plans, working conditions
Extracurricular activities, entertainment	Peers, Internet
Discussion for the future	Career, ambitions for the personal and family life
Sleep and body fatigue	Sleep habits, existence of TV or electronic devices in the bedroom
Medications and abuse	Compatible to pSLE pharmaceutical co-administrations, tobacco, alcohol, any abuse
Mental health	Emotions, sentimental upheavals, acquaintance/ acceptance of the pSLE course

**Table 3.** Accompanying medical report of the pSLE patient

- Classification of pSLE criteria (date of fulfillment)
- Initial phenotype (SLEDAI/ECLAM score) - management
- Disease course (SLEDAI/ECLAM score) - regimens - compliance
- Regimen tolerance/drug toxicity
- Time of damage development according to SDI/SLICC (including gonadal dysfunction)
- Latest assessment of disease activity or damage (emphasizing on kidneys, heart, CNS)
- Co-morbidity (atherosclerosis, obesity, osteoporosis)
- Vaccinations/ophthalmology assessment, bone health, contraception
- Academic performance

In the meantime, the patient is getting training on the successful cooperation with the care providers' team, including the pediatric rheumatologist, pediatric nephrologist and other physicians or health professionals, such as psychologists. This teamwork will lead the family and the patient to give their consent and co-decide on any medical decision.<sup>10-12</sup> During the course of the disease, pSLE can affect not only the patient's emotional state, but also higher cognitive functions, such as the synthesis of ideas, and the attitude towards the challenges of life in respect to professional and social rehabilitation. Therefore, the patient deserves to be supported by specialists experienced on the characteristics of pSLE.<sup>4, 7,9,15,16</sup>

Most adolescents seek additional health-related information online.<sup>17</sup> For Greek patients, there are reliable web sources written in the Greek language that originate from well-known Rheumatology Organizations/Societies such as [www.printo.it](http://www.printo.it) and [www.tosomasoumilaei.gr](http://www.tosomasoumilaei.gr). These trustworthy sites contribute to the development of ranking the reliability of websites containing disease related information.

### Transfer to the adult Rheumatology Clinic

The optimal timing of the final transfer to an adult Rheumatology Clinic is when the patient is in clinical remission and has a proven ability to self-manage his/her life and cope with his/her difficult and unpredictable chronic diseases.<sup>14,18,19</sup>

The final steps towards adult Rheumatologists are escorted by a medical report delineating the patient's disease phenotype that is addressed to the adult physician in case that they had not previously evaluated the patient in a joint Clinic (**Table 3**).<sup>4,11,18,19</sup>

Finally, if the patient wishes so, his/her parents may be present at his/her entrance to the novel healthcare setting, in order to be both ensured for the well-scheduled ongoing of the disease monitoring.<sup>10,19</sup>

### CONFLICT OF INTEREST

The author declares no conflict of interest.

### REFERENCES

1. Silva C A, Avcin T, Brunner H I. Taxonomy for systemic lupus erythematosus with onset before adulthood. *Arthritis Care Res (Hoboken)* 2012;64:1787-93.
2. Ravelli A, Duarte-Salazar C, Buratti S, Reiff A, Bernstein B, Maldonado-Velazquez MR, et al. Assessment of damage in juvenile-onset systemic lupus erythematosus: a multicenter cohort study. *Arthritis Rheum* 2003;49:501-7.
3. Nalbanti P, Stefanidou S, Alfantaki S, Siamopoulou A, Trachana M, Galanopoulou V, et al. A Greek multicenter study comparing the clinical and immunologic phenotypes between adult and juvenile-onset lupus. *Pediatric Rheumatology* 2011;9(Suppl1):P245. <http://www.ped-rheum.com/content/9/S1/P245>.
4. Hollander M C, Sage J M, Greenler A J, Pendl J, Avcin T, Espada G, et al. International consensus for provisions of quality-driven care in childhood onset systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2013;65:1416-23.
5. Koutsonikoli A, Trachana M, Heidich AB, Galanopoulou V, Pratsidou-Gertsis P, Garyphallos A. Dissecting the damage in Northern Greek patients with childhood-onset systemic lupus erythematosus: a retrospective cohort study. *Rheumatol Int* 2015;35:1225-32.
6. Bichile T, Petri M. Prevention and management of co-morbidities in SLE. *Presse Med* 2014;43:e187-e195.
7. Borgia R E, Ezequiel R, Silverman E D. Childhood onset systemic lupus erythematosus: an update. *Curr Opin Rheumatol* 2015;27:483-92.
8. McDonagh J E, Kaufman M. The challenging adolescent. *Rheumatology* 2009; 48:872-5.
9. Kone-Paut I, Piram M, Guillaume S, Tran T A. Lupus in adolescence. *Lupus* 2007;16:606-12.
10. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from Adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182-200.
11. Nagra A, McGinnity P M, Davis N, Salmon A P. Implementing transition: ready steady go. *Arch Dis Child Educ Pract Ed* 2015;100:313-20.
12. Calvo I, Antón J, Bustabad S, Camacho M, de Inocencio J, Gamir M L, et al. Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset. *Rheumatol Int* 2015;35:1615-24.
13. Tunnicliffe D J, Singh-Grewal D, Chaitow J, Mackie F, Manolios N, Lin M W, et al. "Lupus means sacrifices" - the perspectives of adolescents and young adults with systemic lupus erythematosus. *Arthritis Care Res (Hoboken)*. 2016;68:828-37.
14. Mc Donagh J E. Transition of care from paediatric to adult rheumatology. *Arch Dis Child* 2007;92:802-7.
15. Sattoe J N T, Hilberink S R, van Staa A, Bal R. Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *J Adolesc Health* 2014;54:397-403.
16. Knight A, Weiss P, Morales K, Gerdes M, Rearson M, Vickery M, et al. Identifying Differences in Risk Factors for Depression and Anxiety in Pediatric Chronic Disease: A Matched Cross-Sectional Study of Youth with Lupus/Mixed Connective Tissue Disease and Their Peers with Diabetes. *J Pediatr* 2015;167:1397-1403. e1.
17. Leanza F, Hauser D. Teens, technology, and health care. *Prim Care* 2014;41:559-66.
18. Chira P, Ronis T, Ardoin S, White P. Transitioning youth with rheumatic conditions: perspectives of pediatric rheumatology providers in the United States and Canada. *J Rheumatol* 2014;41:768-79.
19. Hilderson D, Moons P, Westhovens R, Wouters C. Attitudes of rheumatology practitioners toward transition and transfer from pediatric to adult healthcare. *Rheumatol Int* 2012;32:3887-96.