Abstract 271 Table 1 Maternal and fetal characteristics of the 19 NL cases

NL case	Maternal ethnic group*	Maternal autoimmune disease	Number of pregnancies	Cardiac involvement	Other involvement
1	Amerindian	None	1	AV block type III	
2	ND	pSS	1	AV block type III	
3	ND	pSS	3	NO	Cutaneous
4	ND	None	1	NO	Cutaneous/hematologic/liver
5	White	pSS	1	AV block type III	
6	White	SLE	1	NO	Cutaneous
7	White	pSS	2	AV block type I	
8	White	SLE	1	AV block type III	
9	White	SLE	1	AV block type III	
10	Mestizo	pSS	1	NO	Cutaneous/hematologic
11	Mestizo	None	1	AV block type III	
12	White	SLE	1	AV block type III	
13	White	SLE	1	NO	Cutaneous
14	ND	SLE	1	NO	Cutaneous
15	White	None	1	AV block type III	
16	White	None	1	AV block type III	
17	Mestizo	SLE	2	AV block type III	
18	White	RA	2	NO	Cutaneous
19	ND	SLE	2	AV block type III	

*: according GLADEL ethnic groups. NL: neonatal lupus; ND: not defined; AV,atrioventricular; SLE:, systemic lupus erythematosus; pSS: primary Sjögren syndrome; RA: Rheumatoid Arthritis.

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271 FREQUENCY OF NEONATAL LUPUS IN REFERENCE CENTERS IN THE MANAGEMENT OF PREGNANCY AND AUTOIMMUNE DISEASES

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Background Neonatal lupus (NL) is a disease in children of mothers who have specific anti-Ro/La IgG autoantibodies by passive transplacental transfer. LN is characterized by skin and cardiac involvement, as well as cytopenias, hepatic or neurological manifestations. NL can be diagnosed intra-uterus or in neonatal period, being self-limiting in several months or be irreversible. Congenital heart block (CHB) in a structurally normal heart, is perhaps the most serious manifestation with an estimated mortality rate of around 19%. Objetives: to estimate the frequency of NL in children of mothers with anti-Ro/La in reference centers in the management of pregnancy and autoimmune diseases in Argentina, and to describe maternal and children features.

Methods A descriptive multicenter study was conducted in reference centers in the management of autoimmune diseases and pregnancy in Argentina. Inclusion criteria were the presence of positive maternal serology anti-Ro/La and at least one pregnancy. Demographic and maternal-fetal clinical data were obtained from the clinical histories and each center completed a data collection form created for this study. We defined a NL case (born or not) who presented, pre and/or postpartum, characteristic skin lesions, cytopenias, cardiac involvement (CHB, endocardial fibroelastosis and dilated cardiomyopathy), hepatic or neurological manifestations. Ethnicity was classified using GLADEL groups. NL frequency was calculated dividing the number NL cases by the number of mothers with positive anti-Ro/La serology.

Results 18 reference centers in the management of autoimmune diseases and pregnancy participated in this study in 7 different geographic areas of Argentina (6 of Buenos Aires, 6 of Cordoba, 1 of Jujuy, 1 of Mendoza, 1 of Santa Fe, 1 of Santiago del Estero and 2 of Tucuman). 193 mothers with positive anti-Ro/La serology were included with 364 pregnancies. 19 cases NL cases were reported (10 diagnosed during

pregnancy and 9 in post-partum. The frequency of NL was estimated at 9.8% [95% CI 6.3–14.9] (CHB=6.2% [IC95% 3.5–10.7]). Table 1 describes the maternal and fetal characteristics of NL cases. The most frequent manifestations were skin (n=7) and cardiac involvement (n=12). In 1 case, there was a history of NL in a previous pregnancy. Of the patients with CHB, 5 required a pacemaker.

Conclusions In conclusion, the frequency of NL in our multicentric cohort is greater than other international cohorts. Differences could be related to genetic/environmental factors as well as methodological limitations and selection bias.

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272 FLUCTUATION, INVISIBILITY, FATIGUE THE BARRIERS TO MAINTAINING EMPLOYMENT IN SLE: RESULTS OF AN ON-LINE SURVEY

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Background It is well-documented that systemic lupus erythematosus (SLE) is associated with high levels of workplace disability and unemployment. The objective of this study was to understand reasons for this and to describe the barriers and facilitators to employment identified by people with SLE to develop appropriate solutions. Unemployment, as well as unsuitable work, has adverse health outcomes.

Methods Adults with SLE completed a UK-specific online survey, through the LUPUS UK website, designed to find out more about the difficulties and successes that people with SLE have in maintaining employment. The survey was predominantly qualitative, to understand participants employment experiences to generate possible solutions.

Results 393 people gave detailed responses to the survey within eight weeks. Every respondent reported a detrimental effect of SLE on their ability to work. 40.45% had left employment because of it. The themes of concern to respondents were unambiguous (i) the difficulties of working (and career damage) with SLE (ii) long-term fear and anxiety overshadowing work/family life (iii) the greater potential to remain in some/employment when modifications of work pattern and support from management and colleagues were available. Anti-disability discrimination was reported as partially helpful but incomplete, omitting many features of lupus disability. SLE-related fatigue, its invisibility and fluctuating nature were felt to be the main barriers to maintaining employment. Many respondents could work only part time, anxiety was high regarding future ability to continue working and financial strains. Many had taken substantial pay reductions and refused offered promotions to preserve their health. Distress due to loss of work and the benefits it brings were reported by every respondent who had left work. Loss of work and the demeaning impact of a widespread lack of understanding of the reasons for workplace disability had a detrimental effect on individuals mental health.

Conclusions SLE presents specific difficulties for maintaining employment fatigue, fluctuation and invisibility not addressed by current anti-discrimination legislation or currently-available reasonable adjustments. This study demonstrates that (i) employment is an important area of concern for people with SLE (ii) SLE has significant detrimental effects on individuals' ability to participate and progress in employment (iii) legislators and employers need information about SLE as invisibility and fluctuation cause hidden problems (ii) more data is needed to inform workplace adjustments if individual distress and societal loss of skills are to be addressed.

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273 SAFETY OF RESEARCH CORES OBTAINED FROM CLINICALLY INDICATED BIOPSIES IN THE ACCELERATING MEDICINES PARTNERSHIP NETWORK

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Background The Accelerating Medicines Partnership (AMP) is a public-private network comprising the National Institutes of Health, medical centers, biopharmaceutical companies and non-profit organizations. The Networks overarching mission is to develop SLE diagnostics and treatments via transcriptomic analysis of cells isolated from renal biopsies. This study addresses the safety of the research component of clinically indicated percutaneous kidney biopsies in anticipation of generalizing these results for real world clinical practice. We focused on one site (NYU METRO) for uniformity of data collection in which all biopsies were done by interventional radiology using an 18 gauge needle.

Methods Patients undergoing kidney biopsies to evaluate proteinuria exceeding 500 mg/day (based on uPCR) were consented to donate research tissue which was acquired via an extra pass or the use of a piece of a core with sufficient glomeruli available for both clinical evaluation and research. Adverse events (AE) within 30 days of biopsy were reported.

Results 98 patients with sufficient research kidney tissue have enrolled through the three Phases of AMP (0=technical, 1=technical translational, 2=ongoing full follow-up): 10 males, 88 females; 68 Non-Hispanic (69.4%), 30 Hispanic (30.6%); 19 Asian (19.4%), 32 Black (32.7%), 46 White (46.9%), 1 other (1.0%). Biopsy classes varied: 5 non-LN (5.1%), 1 Class I (1.0%), 5 Class II (5.1%), 21 Class III (21.4%), 16 Class IV (16.3%), 15 Class V (15.3%), 20 Class III/V (20.4%), 11 Class IV/V (11.2%), 3 Class VI (3.1%), 1 not yet determined. Research biopsy core lengths ranged from 4–19 mm. Eleven patients had an AE (research biopsy core lengths 5 13 mm); 8 were hematomas (only 6 had an extra pass specific for research). Of the 8 patients, 5 were hospitalized, 4 for the hematoma with 1 receiving a transfusion. Neither number of passes nor research core length predicted hematoma. All hematomas resolved within one week. The remaining 3 AEs were unrelated to the biopsy: 1 cardiac event-related death, 1 UTI, 1 fall. This site-specific frequency is similar to that being observed in the overall multisite ongoing Phase 2 AMP Network.

Conclusions Albeit this detailed report is limited to one site, it is consistent with the Network experience. These data support the feasibility and safety of obtaining a research core to bring personalized medicine to the management of LN.

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