In 2018 in Chicago, I helped organize the RP Foundation's reception, co-hosted an event with the University of Michigan Division of Rheumatology, participated on a podcast of a news source dedicated to the rheumatology field, and facilitated two exhibitor booths at a prominent rheumatology conference.

In 2019 in Atlanta, I participated in an RP investigator meeting, which provided an update on a classification criteria project, introduced a new project to modify the disease activity index, and summarized RP-related projects.

With knowledge gleaned at these sessions, my husband and I collaborated with the RP Foundation to provide a substantial gift in 2020 to establish the Penn RP Fund, which will support a unique partnership between the University of Pennsylvania and the National Institutes of Health sponsored Vasculitis Clinical Research Consortium.

Results: Living with the purpose of helping other patients continues to improve the quality of my life. It affords me the ability to be excited about the extraordinary advances in patient care and cutting-edge research.

Participating in these conferences has provided exceptional opportunities to learn and collaborate with highly skilled research scientists. Further, I was able to build relationships with these scientists, which played a key role in the launch of the Penn RP Program.

This program will allow researchers to pursue important projects, including the development of a world-class referral center to examine the impact of the microbiome on RP disease activity. Additionally, patients with RP will have the opportunity to be evaluated by multiple subspecialties in a coordinated patient-centered manner.

Conclusion: The RP Foundation, University of Pennsylvania, and the Vasculitis Clinical Research Consortium (VCRC) Created a Powerhouse Healthcare Coalition. The Penn RP program will significantly improve the quality of my life and other RP patients for years to come.

Nancy Linn

The Relapsing Polychondritis Foundation formed a powerhouse healthcare coalition with the University of Pennsylvania and the NIH sponsored Vasculitis Clinical Research Consortium

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Arthritis research

POS1499-PARE PATIENT PERSPECTIVES OF BIOLOGIC TREATMENTS FOR AXIAL SPONDYLOARTHRITIS: SATISFACTION, WEAR-OFF BETWEEN DOSES, AND USE OF SUPPLEMENTAL MEDICATIONS

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Background: Biologic disease-modifying antirheumatic drug (bDMARD) therapy has been shown to be effective in the treatment of axial spondyloarthritis (axSpA).^{1,2} Little is understood about patients' experience of axSpA treatment from their own perspective.

Objectives: To characterize patient experiences and perspectives with bDMARD treatments for axSpA, including satisfaction, and use of supplementary treatments when wear-off between doses is perceived among those currently treated with bDMARD therapy.

Methods: Adult US participants (pts) within the ArthritisPower registry with physician-diagnosed axSpA were invited to complete electronic PRO measures, such as the BASDAI (0-10 scale, score ≥ 4 indicates suboptimal disease control), and an online survey about their perspectives of treatment. Analysis compared pt characteristics and treatment satisfaction by whether or not pt reported wear-off between bDMARD doses.

Results: 128 pts with axSpA and on bDMARD therapy met inclusion criteria of whom 82.8% were female, with mean age of 47 years. Mean BASDAI scores indicated poor disease control (6.4, SD 1.8), worse for those perceiving wear-off between doses compared with those who did not [6.8 (1.6) vs. 5.9 (2.0), $p=0.01$]. A majority of pts on a bDMARD reported being somewhat (57.8%) or very satisfied (26.6%) with their current axSpA treatment, and about 53.1% were satisfied with how well it controls axSpA-related pain. However, 60.9% ($n=78$) of pts reported that their current bDMARD typically wears off before the next dose. Treatment satisfaction was lower for pts experiencing wear-off compared to pts without wear-off (highly satisfied: 21.8% vs. 34%; somewhat satisfied: 60.3% vs. 54%; dissatisfied: 17.9% vs. 12%). 82.1% ($n=64$) of pts reporting wear-off used additional medications or supplements when that happened, chiefly NSAIDs (68.8%, $n=44$), muscle relaxers (42.2%, $n=27$) and/or opioids (37.5%, $n=24$). Among the 20 pts not satisfied with current axSpA treatment, side effects (6/20, 30.0%), or worry about risk of side effects (2/20, 10%) were the main reasons.

Conclusion: In a predominantly female sample of bDMARD-treated axSpA patients with high disease activity, most expressed satisfaction with treatment. However, most experienced wear-off between doses and took supplementary medications, including opioids, to manage.

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Table 1. Demographic and clinical characteristics by wear-off between bDMARD doses (n=128)

	Pts currently on bDMARD doses (N=128)	Wear-off between bDMARD doses (N=78)	No wear-off / Not sure (N=50)	p-value
	Number or mean (% or SD)			
Age	46.9 (10.3)	46.1 (9.2)	48.2 (11.8)	0.25
Female	106 (82.8)	69 (88.5)	37 (74.0)	0.03
White	115 (89.8)	70 (89.7)	45 (90.0)	0.96
Body Mass Index	30.9 (7.8)	31.2 (8.5)	30.4 (6.6)	0.57
Current Medications, addition to bDMARD				
Conventional Synthetic DMARD (e.g. methotrexate, sulfasalazine)	17 (13.3)	15 (19.2)	2 (4.0)	0.01
Prescription NSAID	59 (46.1)	39 (50.0)	20 (40.0)	0.27
Other prescription medication [*]	70 (54.7)	44 (56.4)	26 (52.0)	0.62
Noticed improvement in symptoms related to axSpA since starting current bDMARD	80 (62.5)	51 (65.4)	29 (58.0)	0.40
Noticed improvement in symptoms NOT related to axSpA since starting current bDMARD	40 (31.3)	22 (28.2)	18 (36.0)	0.35
BASDAI [‡]	6.4 (1.8)	6.8 (1.6)	5.9 (2.0)	0.01
PROMIS Pain Interference [‡]	65.3 (5.7)	66.0 (5.1)	64.3 (6.4)	0.09
PROMIS Physical Function [‡]	36.7 (5.6)	36.1 (5.3)	37.7 (5.8)	0.11
PROMIS Sleep Disturbance [‡]	59.8 (8.5)	61.2 (7.7)	57.6 (9.3)	0.02

^{*} Statistical significance between groups of pts who experienced wear-off between bDMARD or not, $p < 0.05$ [‡] Other prescription medications: muscle relaxers, nerve pain medications or anti-depressants, and opioids[‡] BASDAI is scored on a 0-10 scale with score ≥ 4 indicating suboptimal control of disease. PROMIS measures use T-score metric in which 50 is mean, 10 is standard deviation (SD), of US population; higher T-score = more of concept measured

Figure 1. Satisfaction with axSpA treatment by wear-off between bDMARD doses (n=128)

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