

# Advocacy to Improve the Healthcare Experience in Patients With Chronic Inflammatory Diseases



**Association of Women in Rheumatology**  
Saturday, August 17, 2019



## Medical Speakers



***Jeffrey Stark, MD***

Head of U.S. Medical Affairs – Rheumatology  
UCB Pharma  
Smyrna, GA



***Anca Pop, MD***

Head of U.S. Medical Affairs – Gastroenterology  
UCB Pharma  
Smyrna, GA

## Disclosure Information

- This is an educational program sponsored by UCB
- All speakers and workshop facilitators are employees of UCB
- The information contained within this presentation is for your educational purposes only. The examples of advocacy are based on expert opinion and are not directive of engagement in advocacy activities
- Although patient cases within this presentation are based on real-life scenarios, the patient identities are fictional and for illustrative purposes only. They are not intended to suggest the use of any specific treatments or classes of therapy
- Healthcare providers should exercise their professional judgment when treating their own patients

# Outline

- Describe the burden of disease and evaluate the challenges associated with obtaining appropriate health care in patients with chronic inflammatory diseases
- Recognize opportunities available for healthcare providers to advocate for patients with chronic inflammatory diseases
- Advocacy workshop: Identify specific advocacy strategies to address the identified challenges of this patient population



# **THE IMPACT OF CHRONIC INFLAMMATORY DISEASES**

# Key Issues for Patients With nr-axSpA



- **~350 of every 100,000** US adults are living with nr-axSpA<sup>1</sup>
- Of patients with nr-axSpA, **~57% are women**<sup>2</sup>



- Patients with axSpA wait an average of **~5-8 years for a diagnosis**<sup>3,4</sup>
- During this time, patients see **multiple different specialists** and may receive **misdiagnoses** and **potentially inappropriate or ineffective therapies**<sup>5</sup>



There is **no ICD code for nr-axSpA**, which can create barriers to insurance coverage for appropriate therapies<sup>6-8</sup>



- Patients with axSpA are much **less likely to receive a biologic therapy** than are patients with RA<sup>5</sup>
- **27%** of patients with axSpA **receive chronic opioid therapy**. Among these patients, **43% receive opioid monotherapy**<sup>9</sup>



- **45%** of patients with axSpA **switch to a less physically demanding job**<sup>10</sup>
- **24%** of patients with axSpA **leave the workforce early**<sup>10</sup>

axSpA, axial spondyloarthritis; ICD, *International Classification of Diseases*; nr-axSpA, non-radiographic axial spondyloarthritis; RA, rheumatoid arthritis.

1. Strand V, et al. *Arthritis Care Res (Hoboken)*. 2013;65(8):1299-1306. 2. Baraliakos X, Braun J. *RMD Open*. 2015;1(suppl 1):e000053. doi: 10.1136/rmdopen-2015-000053.

3. Masson Behar V, et al. *Joint Bone Spine*. 2017;84(4):467-471. 4. Seo MR, et al. *Clin Rheumatol*. 2015;34(8):1397-1405. 5. UCB, Inc. Data on file.

6. Ankylosing spondylitis and other inflammatory spondylopathies. ICD9Data.com website. Available at: <http://www.icd9data.com/2015/Volume1/710-739/720-724/720/default.htm>. Accessed July 23, 2019.

7. Ankylosing spondylitis. ICD10Data.com website. Available at: <https://www.icd10data.com/ICD10CM/Codes/M00-M99/M45-M49/M45->. Accessed July 23, 2019.

8. Other inflammatory spondylopathies. ICD10Data.com website. Available at: <https://www.icd10data.com/ICD10CM/Codes/M00-M99/M45-M49/M46->. Accessed July 23, 2019.

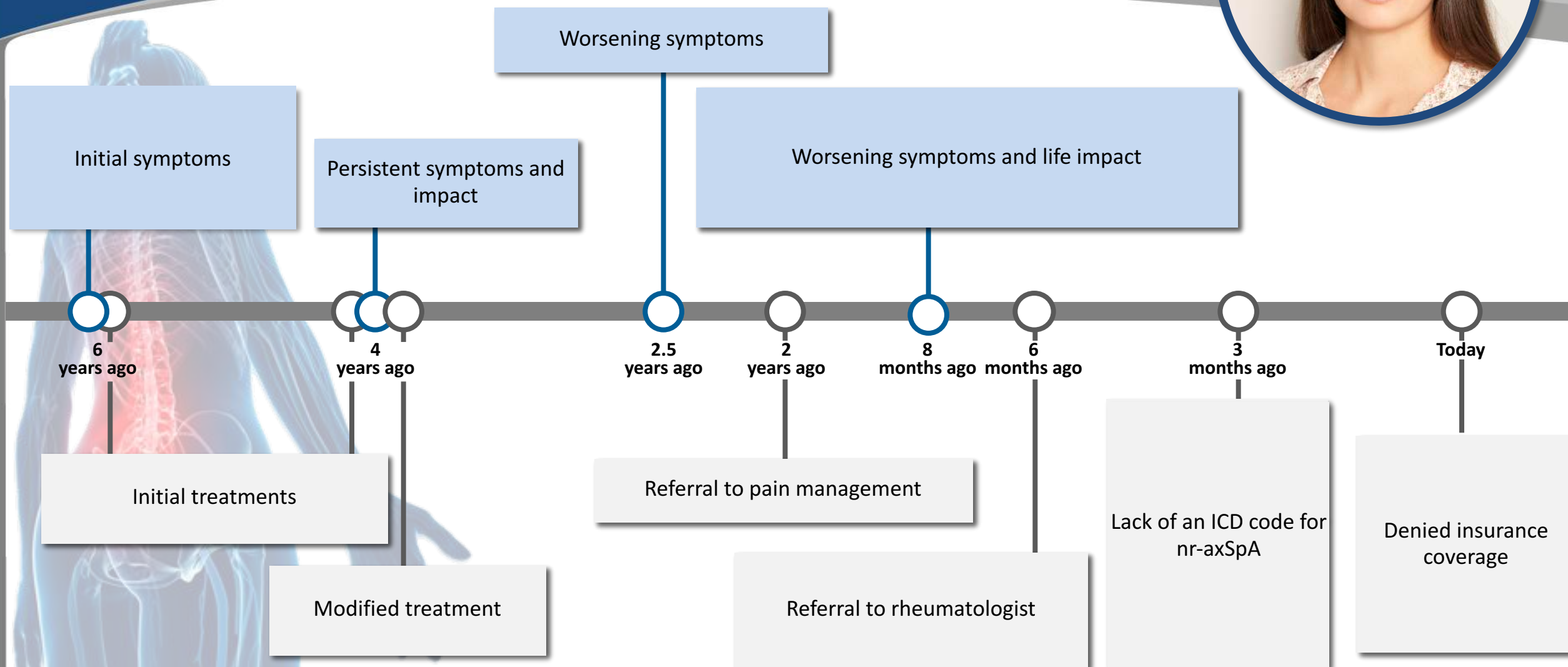
9. Sloan VS, et al. [published online January 15, 2019]. *J Rheumatol*. doi: 10.3899/jrheum.180972. 10. Strand V, Singh JA. *J Clin Rheumatol*. 2017;23(7):383-391.



# nr-axSpA Patient Journey

## Kyra, 32 years old, Graphic Designer

7

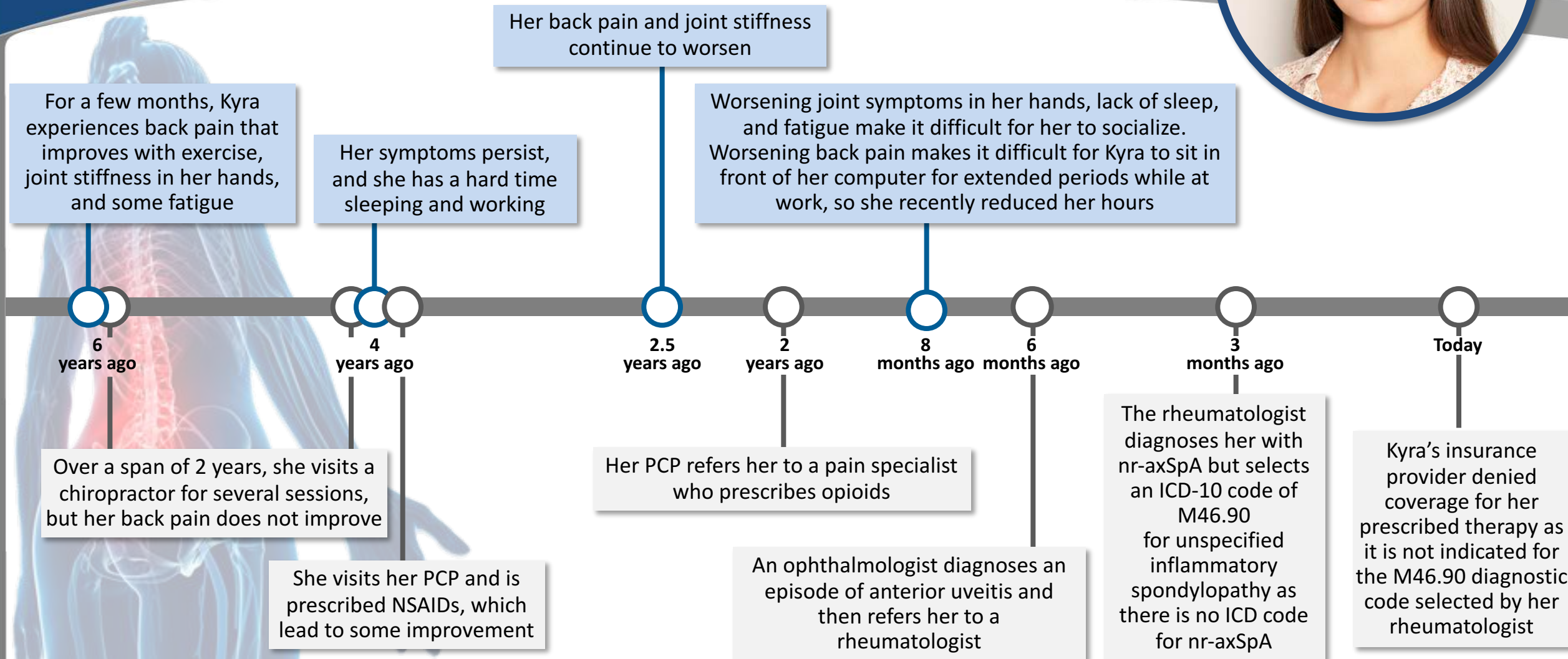


This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.

# nr-axSpA Patient Journey

## Kyra, 32 years old, Graphic Designer

8



This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.



# Key Issues for Patients With PSO-PsA



- **~7 million** adults in the United States live with psoriasis (**PSO**)<sup>1</sup>
- **~1-3 million** individuals in the United States live with psoriatic arthritis (**PsA**)<sup>2,3</sup>



- Almost **one-third** of those with **PSO** develop **PsA**<sup>4</sup>
- 85% of patients develop **PSO** prior to **PsA**<sup>5</sup>



**~70%-80% of dermatologists do not prescribe biologic therapies** for patients with PSO or PsA<sup>6</sup>



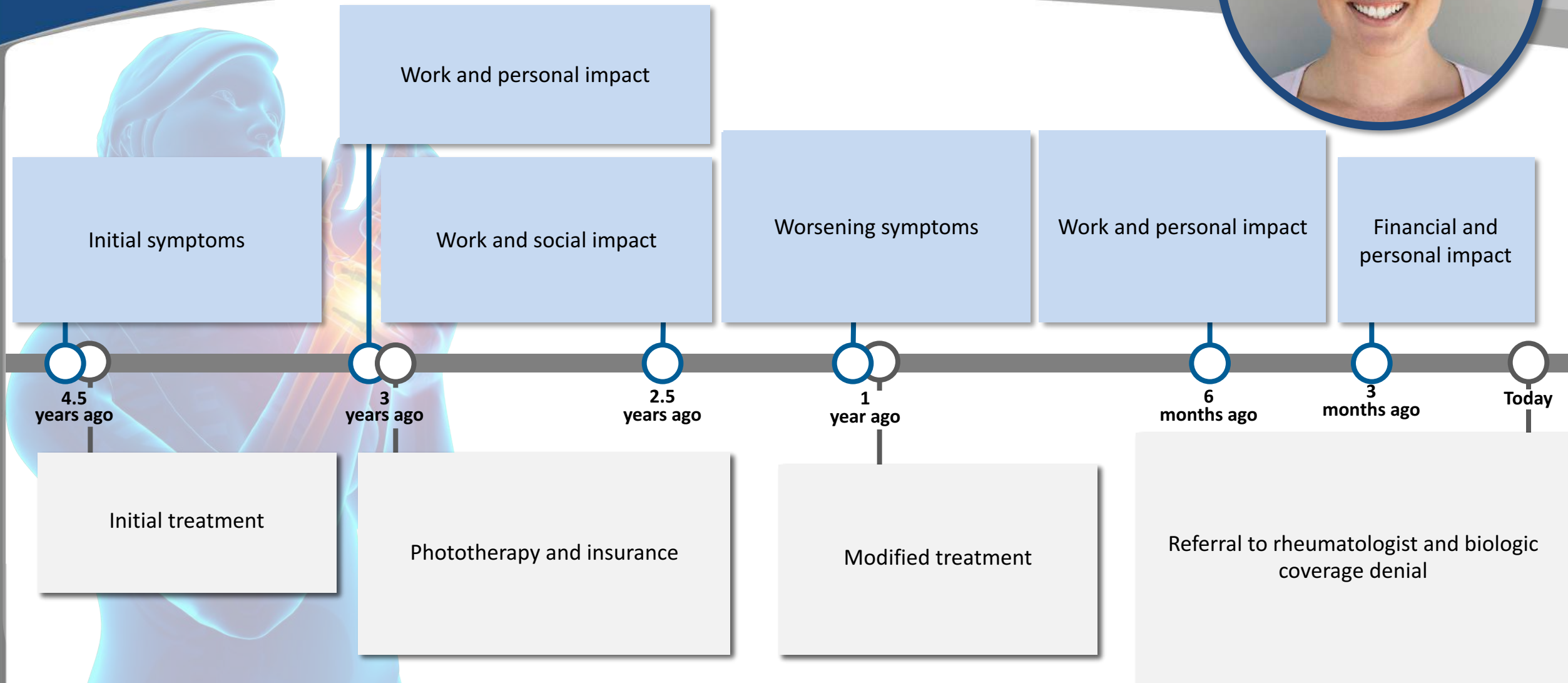
- Compared with the general population, patients with PSO are **~40%** more likely to experience **depression** and **suicidality**<sup>7</sup>
- Patients with PsA have more than **double the rate of depression** as patients with PSO alone<sup>8</sup>
- Patients with PSO have a **lower rate of depression** when their **disease is controlled**<sup>9</sup>



In general, **access** to appropriate **support** for **mental health** can be a **challenge**<sup>10</sup>

# PSO-PsA Patient Journey

## Jocelyn, 35 years old, Cosmetologist

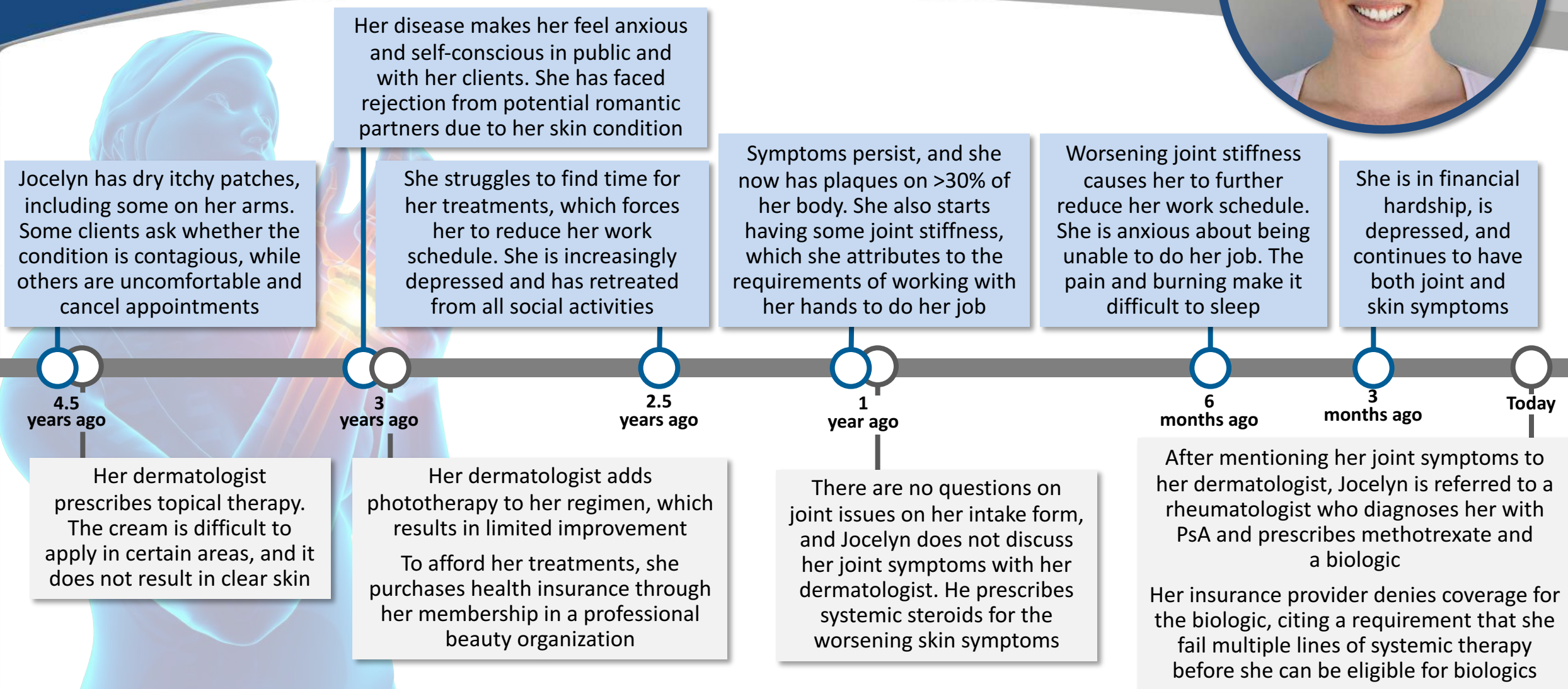


This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.

# PSO-PsA Patient Journey

## Jocelyn, 35 years old, Cosmetologist

11



This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.

# Key Issues for Patients With Crohn's Disease



- ~2 million patients in the **United States** live with **inflammatory bowel disease (IBD)**<sup>1</sup>
- ~800,000 patients in the **United States** live with **Crohn's disease (CD)**<sup>1</sup>



- Generally, **step-up therapy** is recommended by the ACG and AGA treatment guidelines and is **preferred by payers**<sup>2-5</sup>
- For patients with factors suggestive of an **aggressive disease course**, a **top-down approach** may be considered<sup>2,6</sup>
- **Medical nutrition therapy** may be prescribed by physicians **but may not be covered** by insurance<sup>7-9</sup>



**High out-of-pocket costs** may contribute to **nonadherence**<sup>10-12</sup>



Patients with CD may experience **fear of incontinence**, **reduced social function**, **loss of productivity**, and **psychological stress**<sup>13-17</sup>



**Inadequate access to bathrooms** can be a major challenge<sup>16,17</sup>

ACG, American College of Gastroenterology; AGA, American Gastroenterological Association.

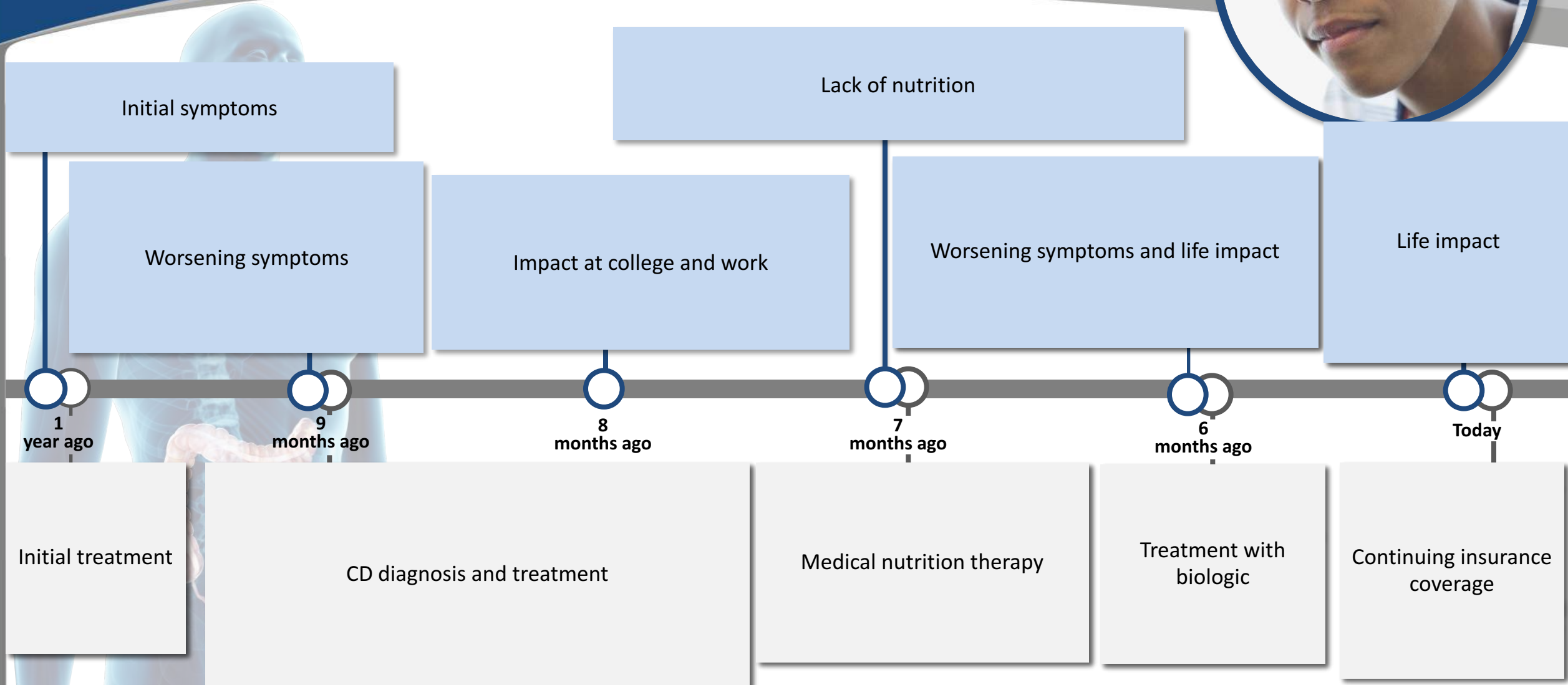
1. Shivashankar R, et al. *Clin Gastroenterol Hepatol*. 2017;15(6):857-863. 2. Tsui JJ, et al. *Ann Gastroenterol*. 2018;31(4):413-424. 3. Lichtenstein GR, et al. *Am J Gastroenterol*. 2009;104(2):465-483. 4. Terdiman JP, et al. *Gastroenterology*. 2013;145(6):1459-1463. 5. Yadav A, et al. *Inflamm Bowel Dis*. 2017;23(6):853-857. 6. Sandborn WJ. *Gastroenterology*. 2014;147(3):702-705. 7. Mayo Clinic. Crohn's disease. Available at: <https://www.mayoclinic.org/diseases-conditions/crohns-disease/diagnosis-treatment/drc-20353309>. Updated June 26, 2019. Accessed July 17, 2019. 8. U.S. Centers for Medicare & Medicaid Services. Nutrition therapy services. Available at: <https://www.medicare.gov/coverage/nutrition-therapy-services>. Accessed July 17, 2019. 9. UnitedHealthcare. Medicare Advantage Policy Guideline. Medical nutrition therapy (NCD 180.1). Available at: <https://www.uhcprovider.com/content/dam/provider/docs/public/policies/medadv-guidelines/m/medical-nutrition-therapy.pdf>. Updated January 9, 2019. Accessed July 17, 2019. 10. Wentworth BJ, et al. [published online April 13, 2018]. *Inflamm Bowel Dis*. doi: 10.1093/ibd/izy102. 11. Viswanathan M, et al. *Ann Intern Med*. 2012;157(11):785-795. 12. Park KT, et al. [published online May 21, 2019]. *Inflamm Bowel Dis*. doi: 10.1093/ibd/izz104. 13. Crohn's & Colitis Foundation of America. *The Facts About Inflammatory Bowel Diseases*. Available at: <http://www.cdfa.org/assets/pdfs/updatedibdfactbook.pdf>. Published November 2014. Accessed July 11, 2019. 14. Cohen RD. *Aliment Pharmacol Ther*. 2002;16(9):1603-1609. 15. Kemp K, et al. *World J Gastroenterol*. 2012;18(43):6240-6249. 16. Bray J, et al. *Can J Gastroenterol Hepatol*. 2016;2016:9430942. doi: 10.1155/2016/9430942. 17. Benchimol EI, et al. *J Can Assoc Gastroenterol*. 2019;2(suppl 1):S1-S5.



# CD Patient Journey

## Tobias, 20 years old, Barista and College Student

13



This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.



# CD Patient Journey

## Tobias, 20 years old, Barista and College Student



Tobias experiences ~3 liquid or watery stools per day, and he sporadically experiences some pain and cramping

His symptoms worsen, and he experiences  $\geq 7$  liquid or watery stools per day and complains of moderate pain and cramping. He starts arriving late to work, missing some classes, and opting out of social activities

He realizes that the options on the cafeteria menu do not meet his needs and starts decreasing food intake due to fear of painful exacerbations. With lack of appropriate nutrition, he experiences malaise and moderate fatigue

At work, he takes frequent bathroom breaks, which irritates his supervisor, coworkers, and customers  
At college, he is unable to easily find a private bathroom, and he feels embarrassed while using shared facilities

Despite treatment, he continues to experience abdominal pain and diarrhea. Active disease affects his work performance, and he is fired from his job. Active disease also prevents him from taking his mid-semester exams, and he is in danger of failing a number of classes

Tobias is unsure that he can afford both his college expenses and the cost of therapy. He is also disheartened that a lack of facilities is impacting his success at college and his opportunities to work

1  
year ago

9  
months ago

8  
months ago

7  
months ago

6  
months ago

Today

After ruling out an infectious etiology, his PCP prescribes antidiarrheals, which provide temporary relief

His PCP refers him to a gastroenterologist, who diagnoses Tobias with CD. His young age, extensive anatomic involvement, presence of severe rectal disease, and deep ulcers are predictive of an aggressive disease course  
Despite the predictors of severe disease, his insurance provider requires that he fail an initial trial of steroids and azathioprine, which his physician prescribes

His physician determines that he is anemic and malnourished and recommends medical nutrition therapy, but his insurance does not cover the costs. So, Tobias chooses to self-monitor his nutritional choices

Concluding that Tobias has failed the initial therapies, his physician prescribes a biologic. Insurance covers the biologic, but the co-pays are high

Once Tobias graduates, he may come off his parents' health insurance. He is concerned about affording insurance and changes in coverage of his treatments

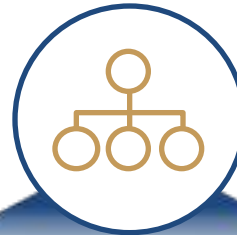
# Key Issues for Women of Childbearing Potential



**1 in 5** individuals in the United States with **RA**, ankylosing spondylitis (**AS**), **PsA**, **PSO**, or **CD** is a **woman of childbearing potential**<sup>1</sup>



Compared with men with these diseases, women with chronic inflammatory diseases report **lower quality of life**, **higher rates of depression and anxiety**, and **lower sexual satisfaction and function**<sup>2-9</sup>



Women with chronic inflammatory diseases are concerned about the **heritability of the disease** and the **possible impact of certain agents on a woman's reproductive journey**<sup>10-12</sup>



- Although there are therapies with **clinical evidence** relating to **women of childbearing potential** that women and their HCPs can consider in shared decision making, **payer step edits may limit access to these options**<sup>13-16</sup>



- Active disease** may be associated with **negative pregnancy outcomes**<sup>17-19</sup>
- It is important to **achieve disease control in all women of childbearing potential** as **~50% of pregnancies** in the general population are unplanned<sup>20</sup>

HCPs, healthcare providers.

1. UCB, Inc. Data on file. 2. Hauser G, et al. *Coll Antropol*. 2011;35(suppl 2):203-207. 3. Reed MD, et al. *Intern Med J*. 2008;38(5):321-327. 4. Matcham F, et al. *Semin Arthritis Rheum*. 2014;44(2):123-130.

5. Eder L, et al. *Ann Rheum Dis*. 2013;72(4):578-582. 6. Panara AJ, et al. *Aliment Pharmacol Ther*. 2014;39(8):802-810. 7. Meesters JJ, et al. *Arthritis Res Ther*. 2014;16(5):418. doi: 10.1186/s13075-014-0418-z.

8. Dowdy SW, et al. *Arthritis Care Res*. 1996;9(6):449-456. 9. Timmer A, et al. *Clin Gastroenterol Hepatol*. 2007;5(1):87-94. 10. Jayasundara M, et al. *Arthritis Rheumatol*. 2017;69(suppl 10): Abstract 1308. Available at:

<https://acrabstracts.org/abstract/answering-reproductive-health-questions-that-your-patients-want-to-know-impediments-to-family-building-and-risks-of-contraception/>. Accessed June 13, 2019.

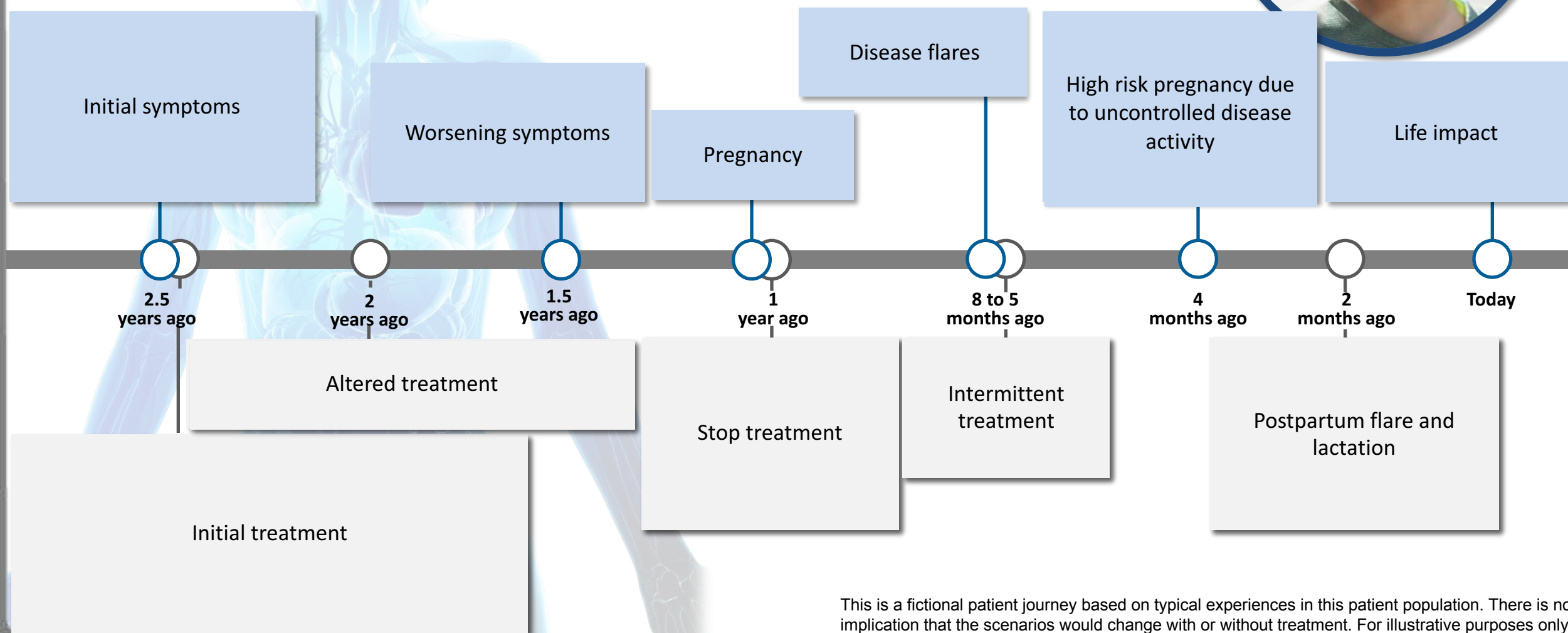
11. Mills B, et al. *Arthritis Rheumatol*. 2017;69(suppl 10): Abstract 355. 12. Marri SR, et al. *Inflamm Bowel Dis*. 2007;13(5):591-599. 13. Marchioni RM, Lichtenstein GR. *World J Gastroenterol*. 2013;19(17):2591-2602. 14. Porter ML, et al. *Int J Womens Dermatol*. 2017;3(1):21-25. 15. Gottlieb AB, et al. *Int J Womens Dermatol*. 2019;5(3):141-150. 16. Singh M, Thorpe KE. Published May 2019. 17. Hashash JG, Kane S. *Gastroenterol Hepatol (N Y)*. 2015;11(2):96-102. 18. Bharti B, et al. *J Rheumatol*.

2015;42(8):1376-1382. 19. Bobotsis R, et al. *Br J Dermatol*. 2016;175(3):464-472. 20. Finer LB, Zolna MR. *Contraception*. 2011;84(5):478-485.

# Woman of Childbearing Potential Patient Journey

## Meera, 30 years old, College Professor

16



This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.



# Woman of Childbearing Potential Patient Journey

## Meera, 30 years old, College Professor

17



Meera experiences severe disease symptoms associated with her chronic inflammatory disease, which affect her daily life, ability to enjoy hobbies, and ability to socialize with friends

2.5  
years ago

Despite feeling well during the first 6 months of therapy, she starts to experience symptoms again and feels poorly

2  
years ago

1.5  
years ago

She unexpectedly finds out that she is pregnant

1  
year ago

Her disease flares multiple times during pregnancy

8 to 5  
months ago

Meera enters the third trimester. Her physician counsels that she is in the high risk pregnancy category because of her uncontrolled disease activity

4  
months ago

She is worried about her ability to simultaneously take care of her family and cope with her disease

2  
months ago

Today

Her insurance provider changes its formulary and no longer covers her therapy. She is forced to settle for another agent

She discusses therapeutic options with her doctor that will support her life goals, including traveling internationally and starting a family in the future. She is uncomfortable with some therapies, given the chance she could become pregnant. She and her physician select an agent that her insurance provider covers

She decides to stop her therapy without discussing the decision with her physician, especially because she feels the treatment is not working

Her physician intermittently prescribes steroids to manage the flares

She has a disease flare within a few weeks of giving birth. Despite active disease postpartum, she decides against restarting her therapy while breastfeeding her infant son

This is a fictional patient journey based on typical experiences in this patient population. There is no implication that the scenarios would change with or without treatment. For illustrative purposes only.

## Patient Profiles: Summary of Key Challenges



How can we help Meera avoid unnecessary non-medical switching?



How can we help Tobias receive better access to facilities?



How can we help Jocelyn get earlier access to effective therapy for her disease?



How can we help Kyra access the most appropriate therapy for nr-axSpA?



The background is a light blue gradient with a faint, stylized outline of the United States map. Various medical icons are scattered around the map, including a caduceus in the top left, a pill in the top center, a heart with an ECG line in the top right, a syringe in the bottom left, a stethoscope in the bottom center, and a bandage in the bottom right. A horizontal band of light beige color runs across the middle of the image, serving as a backdrop for the title text.

# **ADVOCACY FOR PATIENTS WITH CHRONIC INFLAMMATORY DISEASES**

## Advocacy Speaker



***Kristi Lengyel***

Head of US Patient Advocacy  
UCB Pharma  
Smyrna, GA

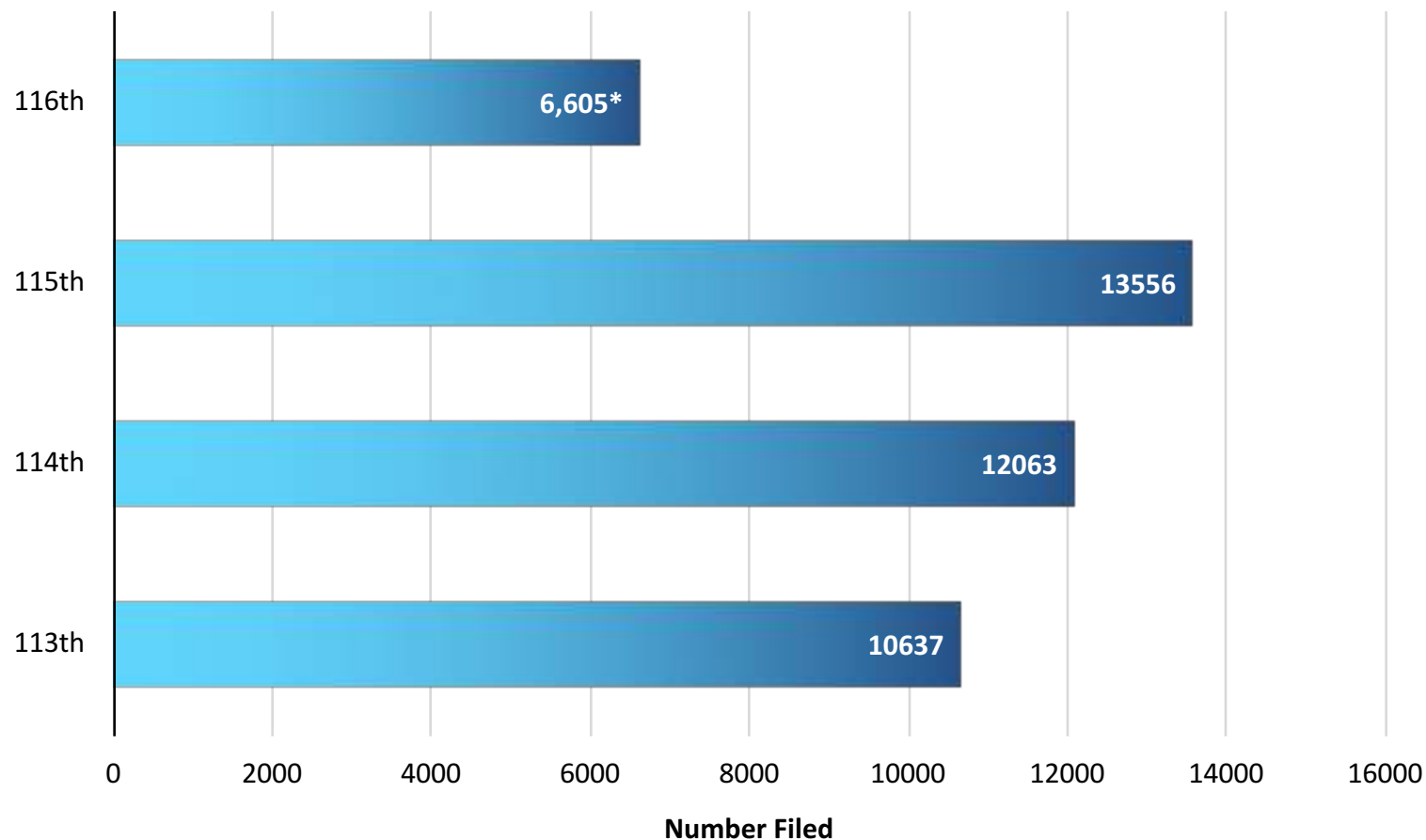
# What is advocacy?



# Why is advocacy important?



Total Federal Bills and Resolutions Introduced Each Congress<sup>1</sup>



1. Govtrack. Statistics and Historical Comparison. <https://www.govtrack.us/congress/bills/statistics>. Accessed July 8, 2019.

\*Note – 116th Congress data includes all bills and resolutions filed up until July 2, 2019.

## How can advocacy help balance the scales?



Builds relationships



Establishes credibility



Protects interests

The examples of advocacy are based on expert opinion and are not directive of engagement in advocacy activities.



# What are the issues for patients with chronic inflammatory diseases?



## Payer

Utilization management  
Reimbursement  
Affordability



## Policy

Legislation  
Regulation  
Rules/guidance



## Humanistic

Public/personal  
College/work  
Accommodations

# What are the issues for patients with chronic inflammatory diseases?



## Prior Authorization

**66%** of rejected prescriptions at the pharmacy require PA<sup>1</sup>



## Step Therapy

In 2010, nearly **60%** of commercial insurers were using step therapy. As of 2013, **75%** of large employers reported offering plans that use step therapy<sup>2,3</sup>



## Non-medical Switching

A Feb. 2019 study on non-medical switching showed **two-thirds** of chronic disease respondents said the switch impacted their ability to be productive at work, while more than **40%** said they weren't able to care for their children, spouses or other family members as needed<sup>4</sup>



## Out of Pocket

**29%** of US patients delayed health care in 2018 because of high patient financial responsibility<sup>5</sup>

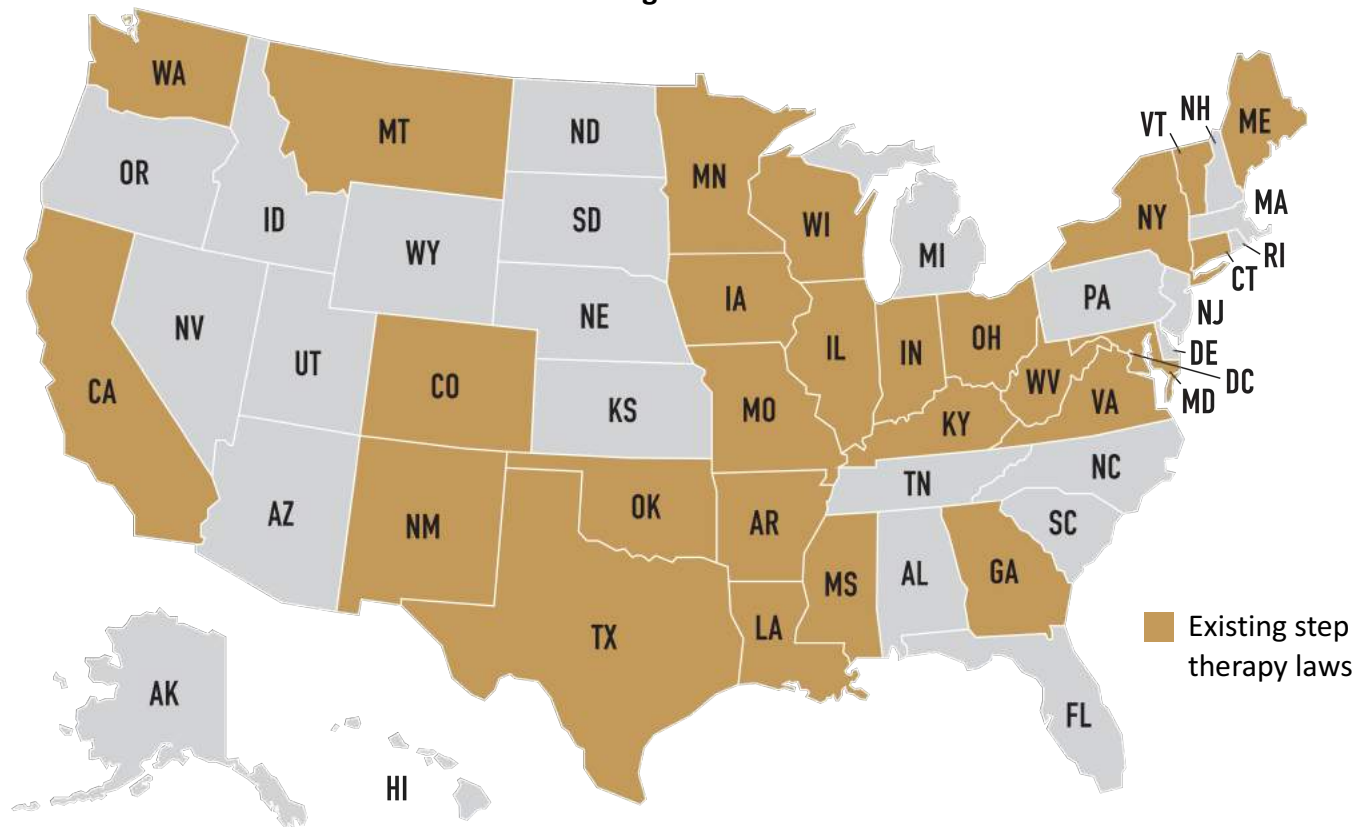
1. CoverMyMeds Analytics, 2017 (Based on two months of paid and rejected data from PioneerRx. Data only considers reject codes 70,75 and MR.) Cision PR Newswire. 2018 ePA National Adoption Scorecard Offers Updated Industry Trends, Research, Data. <https://www.prnewswire.com/news-releases/2018-epa-national-adoption-scorecard-offers-updated-industry-trends-research-data-300600852.html>. Accessed July 9, 2019. 2. Pharmaceutical Step-Therapy Interventions: A Critical Review of the Literature," J Manag Care Pharm. 2011;17(2):143-55. SAIM Coalition. Step Therapy: The Patient Impact. <http://prescriptionprocess.com/wp-content/uploads/2016/12/Step-Therapy-The-Patient-Impact.pdf> Accessed July 9, 2019. 3. Step therapy comeback continues." Journal of Managed Care. September, 2012. Available at <http://www.managedcaremag.com/archives/1209/1209.outlook.html>. Last accessed January 25, 2015. SAIM Coalition. Step Therapy: The Patient Impact. <http://prescriptionprocess.com/wp-content/uploads/2016/12/Step-Therapy-The-Patient-Impact.pdf> Accessed July 9, 2019. 4. Institute for Patient Access. A Study of the Qualitative Impact of Non-Medical Switching. Read Study. Pg3/P1/Non-Medical Switching Impacts Work & Family Life. <https://instituteforpatientaccess.org/a-study-of-the-qualitative-impact-of-non-medical-switching/>. Accessed July 9, 2019. 5. Patient Engagement Hit. Sara Heath. 21 Dec. 2018. High Out-of-Pocket Costs Hamper Care Access for 30% of Patients. <https://patientengagementhit.com/news/high-out-of-pocket-costs-hamper-care-access-for-30-of-patients>. Accessed July 9, 2019.

# How has policy helped to address issues for patients with chronic inflammatory diseases?



## Step Therapy Laws

Figure 1:



Step Therapy

Non-Medical Switching

Ally's Law

Co-Pay Surprise

# What are the issues for patients with chronic inflammatory diseases?



Work



College



Young Adults



Public

# Engaging in advocacy: Examples of provider advocates



## Simple Advocacy

- Petitions
- Op-Ed
- Online testimony
- Phone, email, and social media outlets
- Action alerts
- Colleagues



## High-Level Advocacy

- Committee testimony
- Office & facility tours
- Advisory committees
- Advocacy/Hill Day
- Advocacy committees
- Regulatory comments



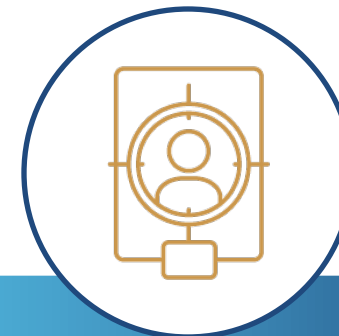
## Engaging in advocacy: Examples for provider advocates to help patients



**Resources**



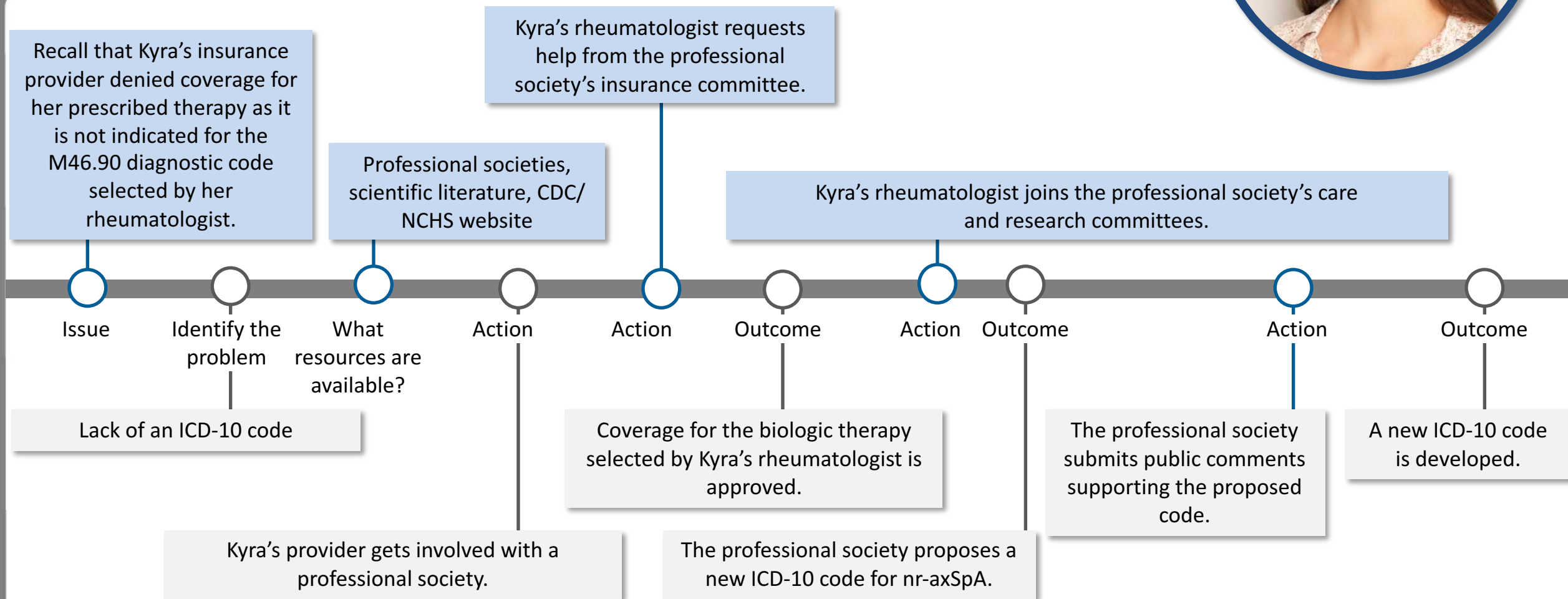
**Connections**



**Identification**

# nr-axSpA Patient Journey

## Kyra, 32 years old, Graphic Designer



# PSO-PsA Patient Journey

## Jocelyn, 35 years old, Cosmetologist



The health plan's fail-first policy is one-size-fits-all and does not account for complex cases.

Recall that Jocelyn is a patient with PSO who develops PsA. Her health plan requires her to "fail first" before approving coverage of a prescribed biologic.

Jocelyn shares her experience with her provider and advocacy organization. She is introduced to a coalition working on the issue.

The coalition develops legislation that accounts for Jocelyn's experience. The legislation is introduced.

Jocelyn engages with stakeholders on social media.

The legislation succeeds and is signed into law.

Background

Issue

Identify the Problem

Resources

Action

Outcome

Action

Action

Action

Outcome

Outcome

Jocelyn's health plan wants her to fail first before approving coverage for the biologic.

Issue-specific coalitions, grassroots mobilization, targeted media

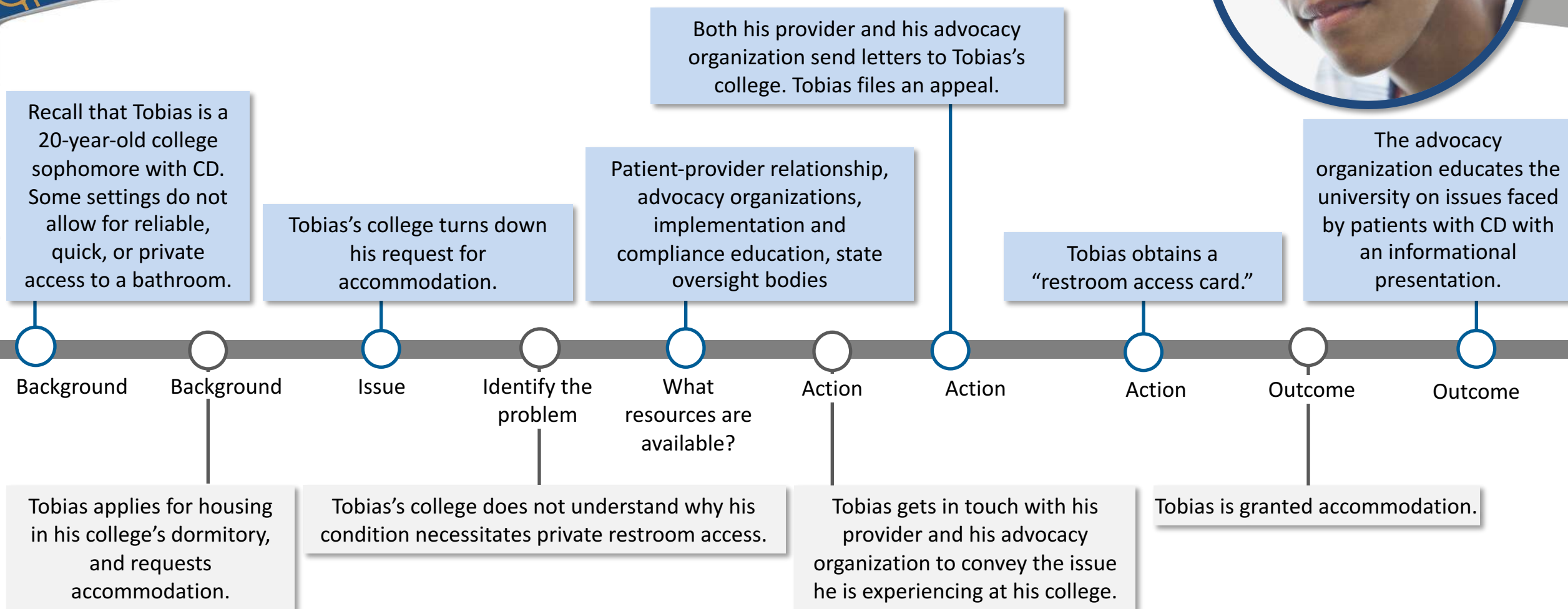
Jocelyn works with a media consultant to publish her experience in key media markets.

Jocelyn participates in a grassroots letter writing campaign.

Patients and providers have streamlined access to appropriate therapies.

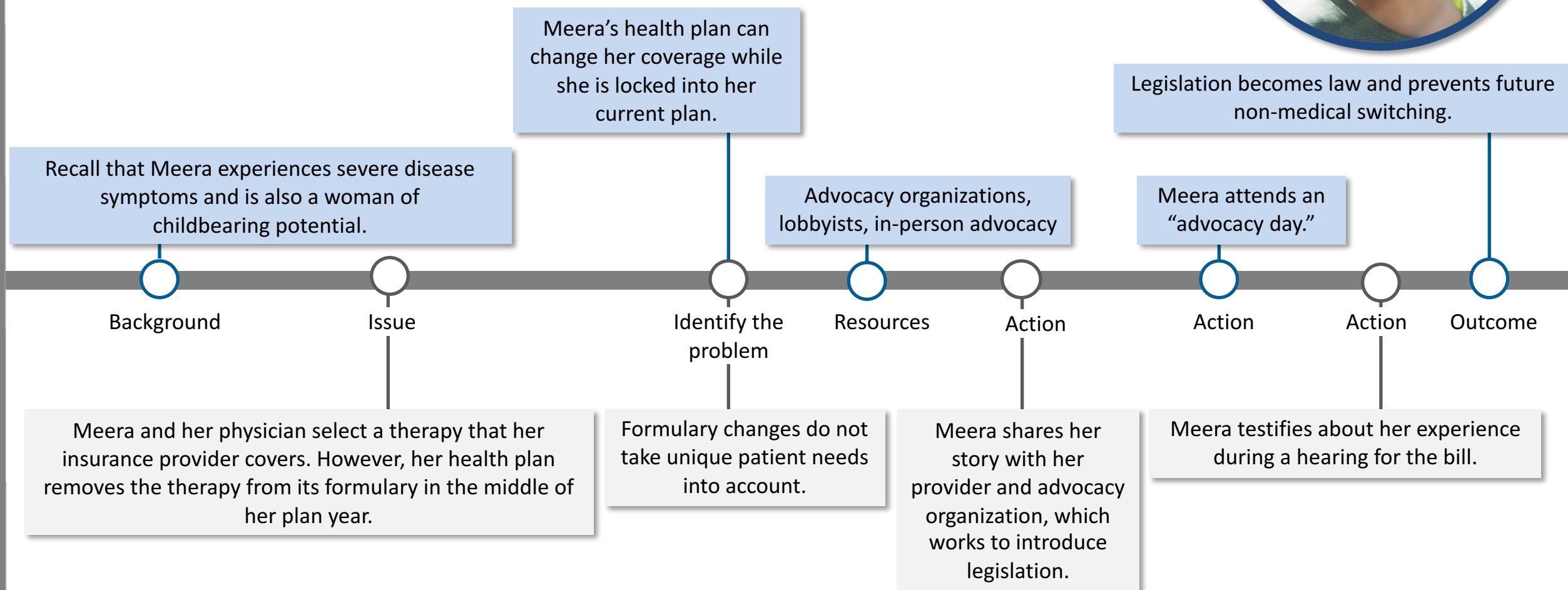
# CD Patient Journey

## Tobias, 20 years old, Barista and College Student



# Woman of Childbearing Potential Patient Journey

## Meera, 30 years old, College Professor





## Remember that...



Access for patients can be shaped through advocacy

The future of medicine can be shaped through advocacy



If we're not at the negotiating table, we leave ourselves and our patients open to unwanted change

As healthcare providers, we have important relationships with local patients who choose legislators, making our real-world input vital to developing proficient legislators





# Questions?