

Overcoming Hurdles

Insurance, Scripts, and Specialty Pharmacy

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Welcome to the TSC Alliance Webinar Presentation!

Introducing...

+ ENGAGE



Julie Scroggins

Community Programs Manager, West
TSC Alliance

Ashley Pounders
MSN, FNP-C

Director, Medical Affairs,
TSC Alliance



Jeff Krol

Market Access and
Payer Strategy Expert



About this tool

This tool is intended to help you overcome potential hurdles that you may find on your tuberous sclerosis complex (TSC) journey.

Here you will find information about:

- Drug therapies to treat the specific symptoms that a patient with TSC may experience
- Common health insurance terms
- Payer organizations—how they make coverage decisions and use terms to help you understand the payer coverage decision-making process
- Specialty pharmacies—how your prescription gets filled by them and potential resources if you cannot afford your prescription
- How the TSC Alliance can help you along your way
- Tips to help you navigate the healthcare system through the transition from childhood to adulthood

LET'S GET STARTED



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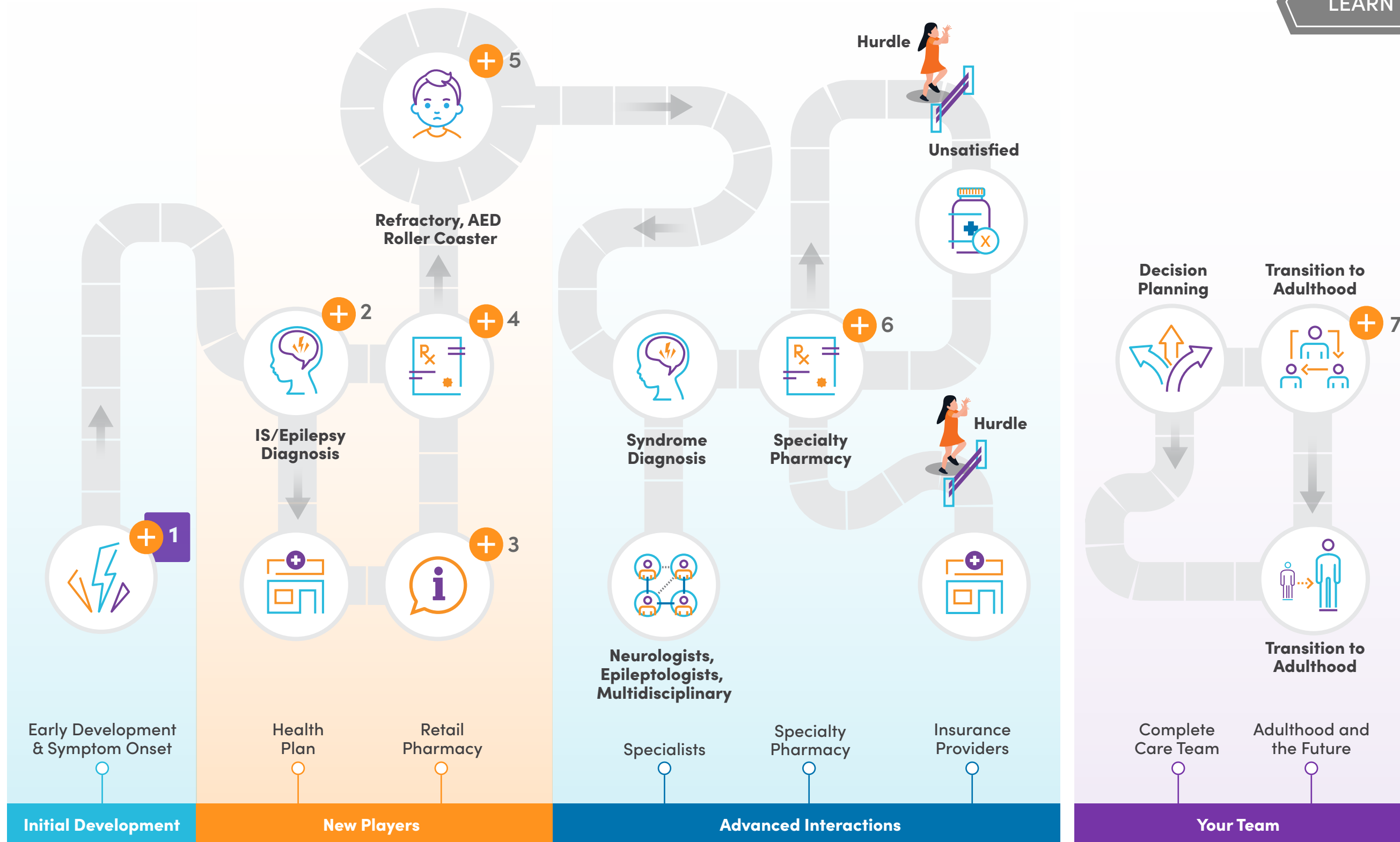


Listen to the podcast on Overcoming Hurdles with Health Plans and Specialty Pharmacies.

Potential Hurdles in the TSC Journey

Click on icon **1** below to learn more and begin the journey

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Potential Hurdles in the TSC Journey

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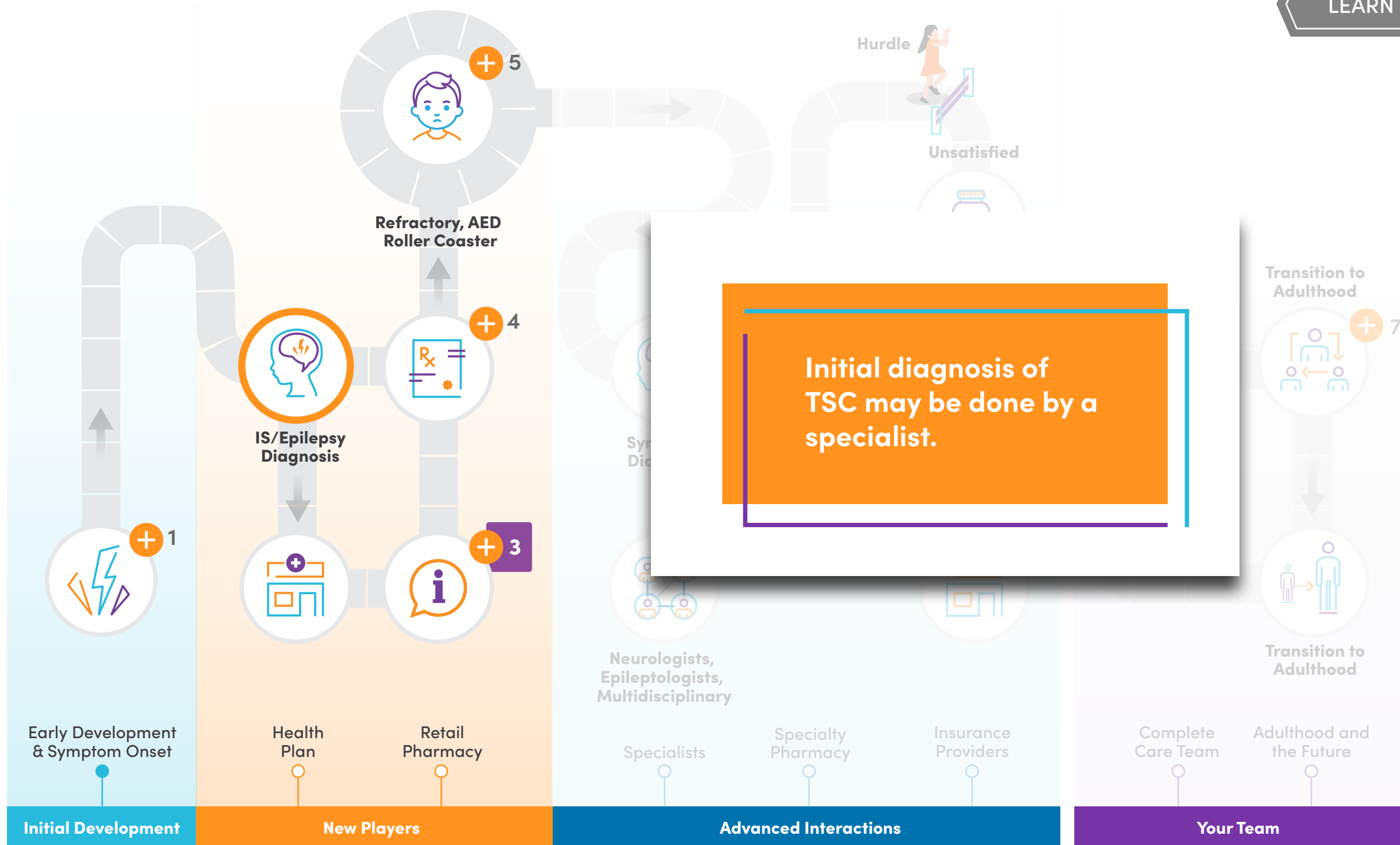


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Potential Hurdles in the TSC Journey

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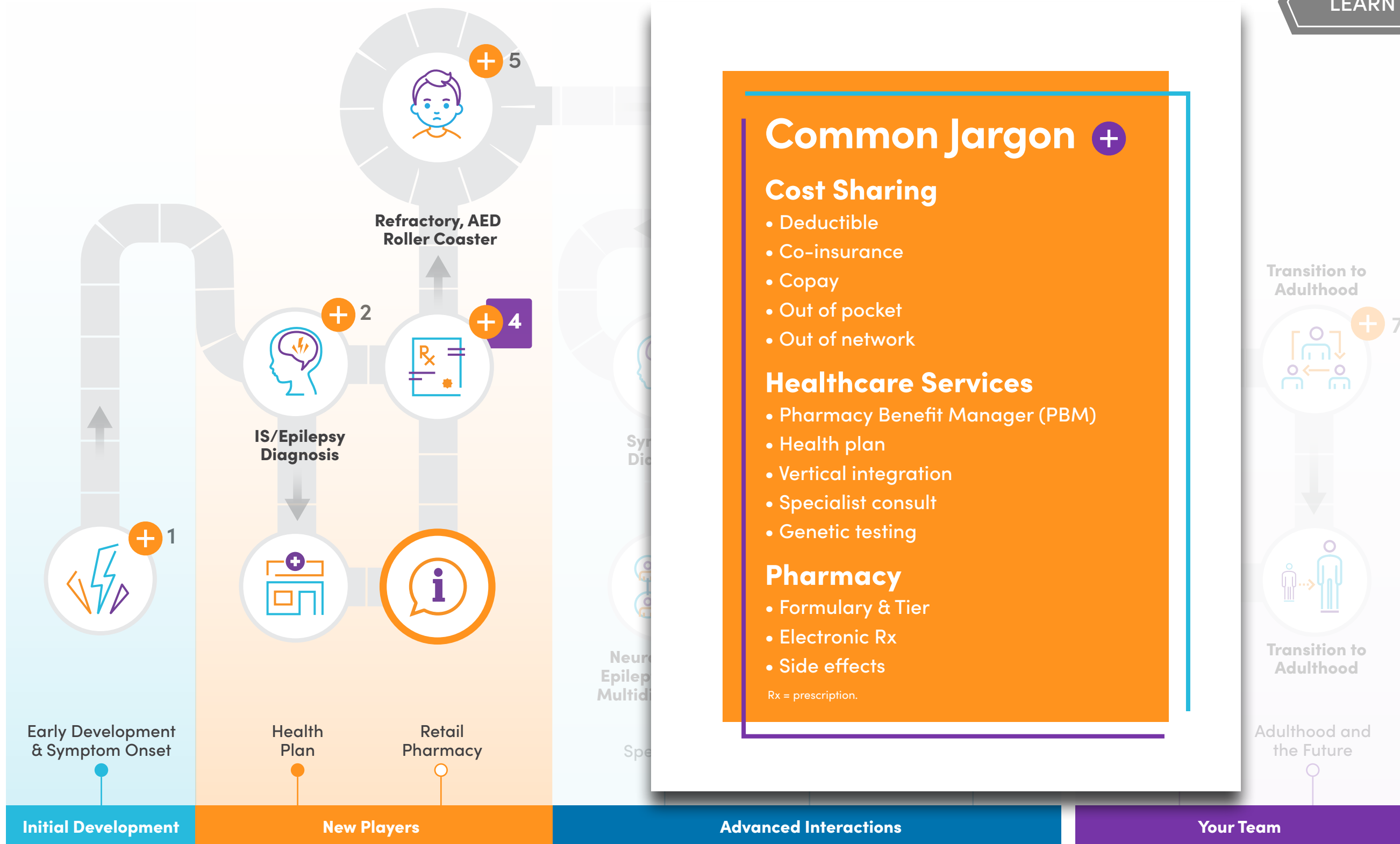


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Potential Hurdles in the TSC Journey

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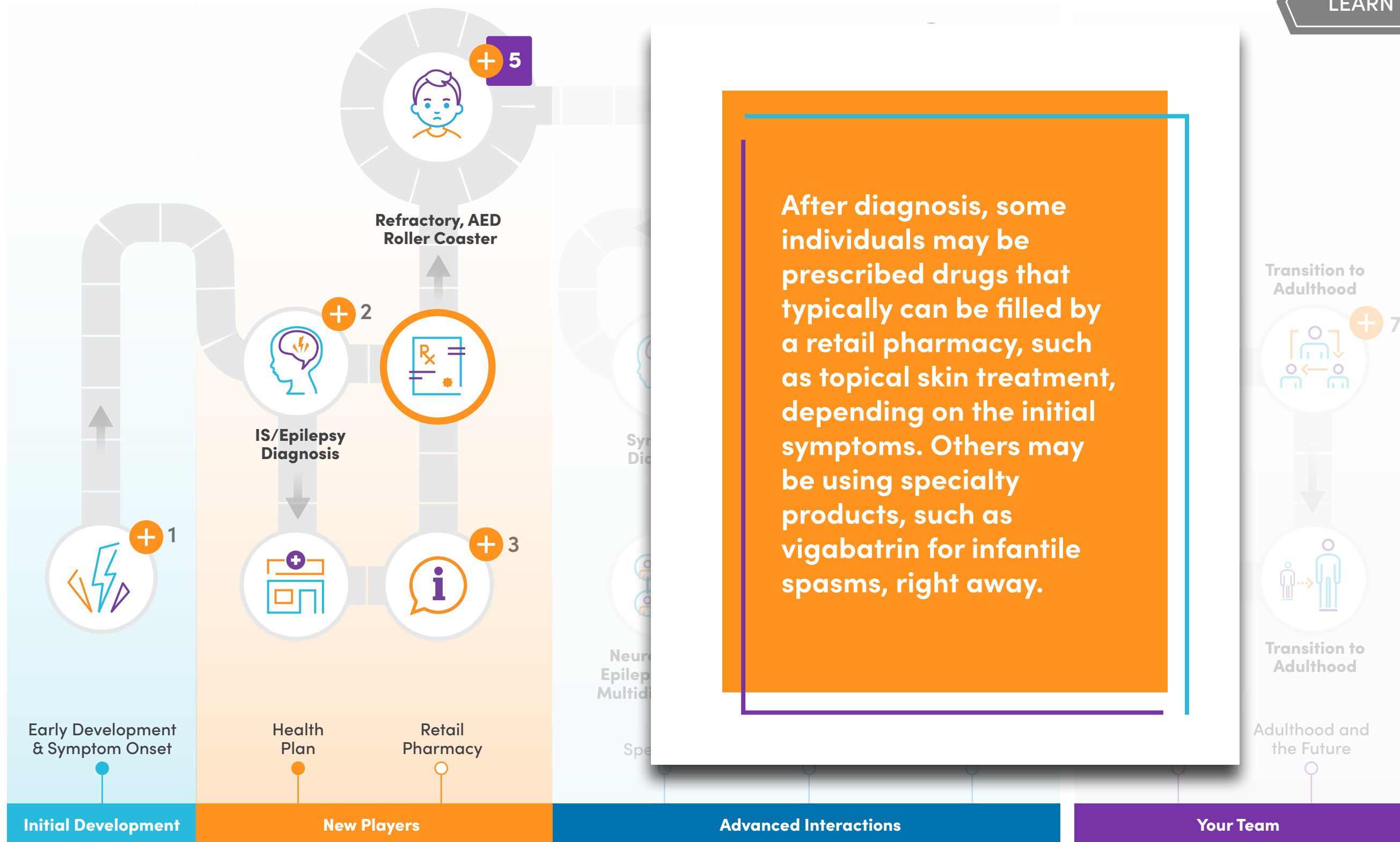


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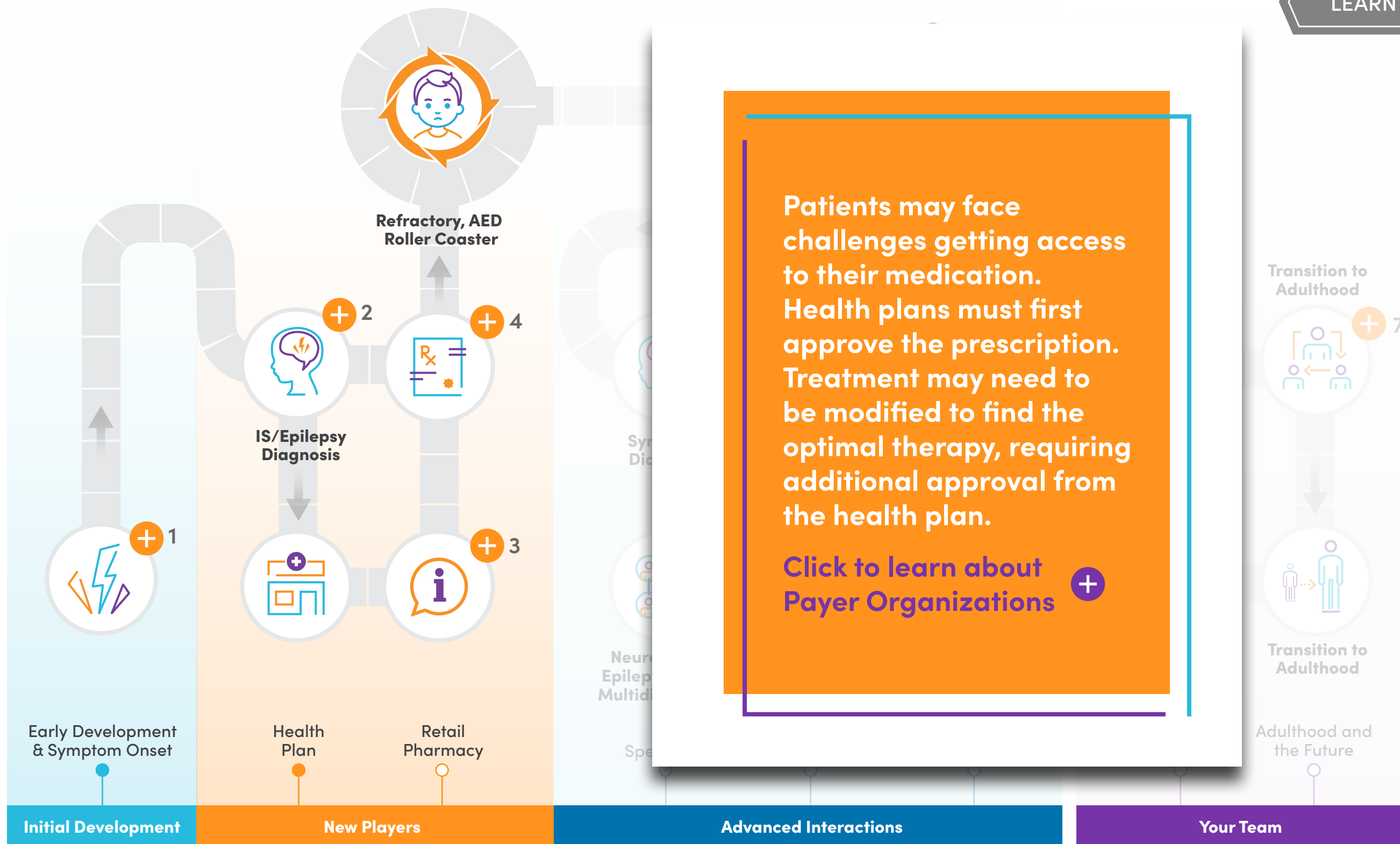




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Payer Organizations





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Integrated Payer Organizations

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All 5 of the top specialty pharmacies are fully or partially owned by one of the largest PBMs and vertically integrated into large organizations

Insurer

UnitedHealthcare®
A UnitedHealth Group Company

aetnaSM

Cigna®

Anthem. 

Humana.

 BlueCross®
BlueShield®

PBM

 OPTUM Rx®

 CVS caremark®

 EXPRESS SCRIPTS®

ingenio RxSM

Humana
Pharmacy Solutions

 PRIME
THERAPEUTICS®

Specialty
Pharmacy

 brioRx®

 CVS specialty™

accredo®

 CVS specialty™

Humana
Pharmacy

allianceRx
Walgreens + PRIME

Provider
Services

 OPTUM Care®

 CVS minute clinic®

Cigna

 CareMore
HEALTH

 Partners in
Primary Care.

 CONVIVA
Care Center

 Kindred
Healthcare



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Who Makes Coverage Decisions?

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The decision of what drugs are covered by a plan is made by a Pharmacy & Therapeutics (P&T) Committee

Responsibilities include:



P&T Committee

Formulary system maintenance

Medication selection and review

Medication use evaluation

Medication safety evaluation

Drug therapy guidelines

Utilization management

Education

The P&T Committee is made up of:

- Physicians (Medical Directors)
- Pharmacists
- Nurses

Representing specialties such as:

- Immunology
- Oncology
- Dermatology
- Infectious disease
- Neurology

The P&T Committee:

- Determines formulary and utilization management criteria
- Meets several times annually
- Decisions are then taken downstream to health plans, employer groups, and members



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How Are Decisions Made?

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Review Clinical Data

- FDA label
- Published data
- Clinical guidelines
- Key opinion leaders



Review Financial Impact

- Burden of illness
(including indirect and
direct healthcare costs,
hospitalizations, ER
visits, etc)
- Unit cost
- Discounts and rebates
from manufacturers



Apply Management Controls +

- Specialty or retail
pharmacy
- Tier/out-of-pocket costs
- Utilization management
criteria

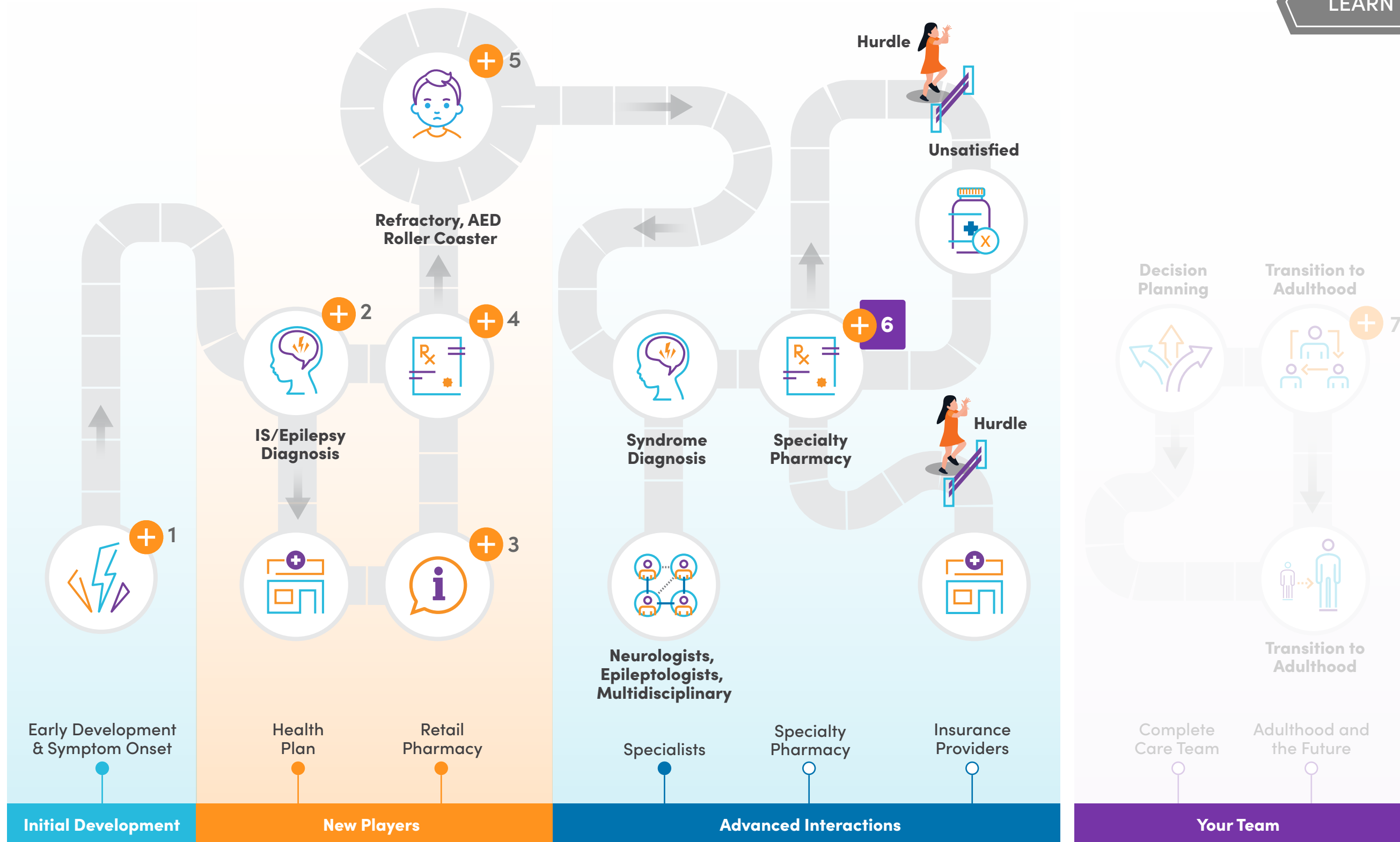


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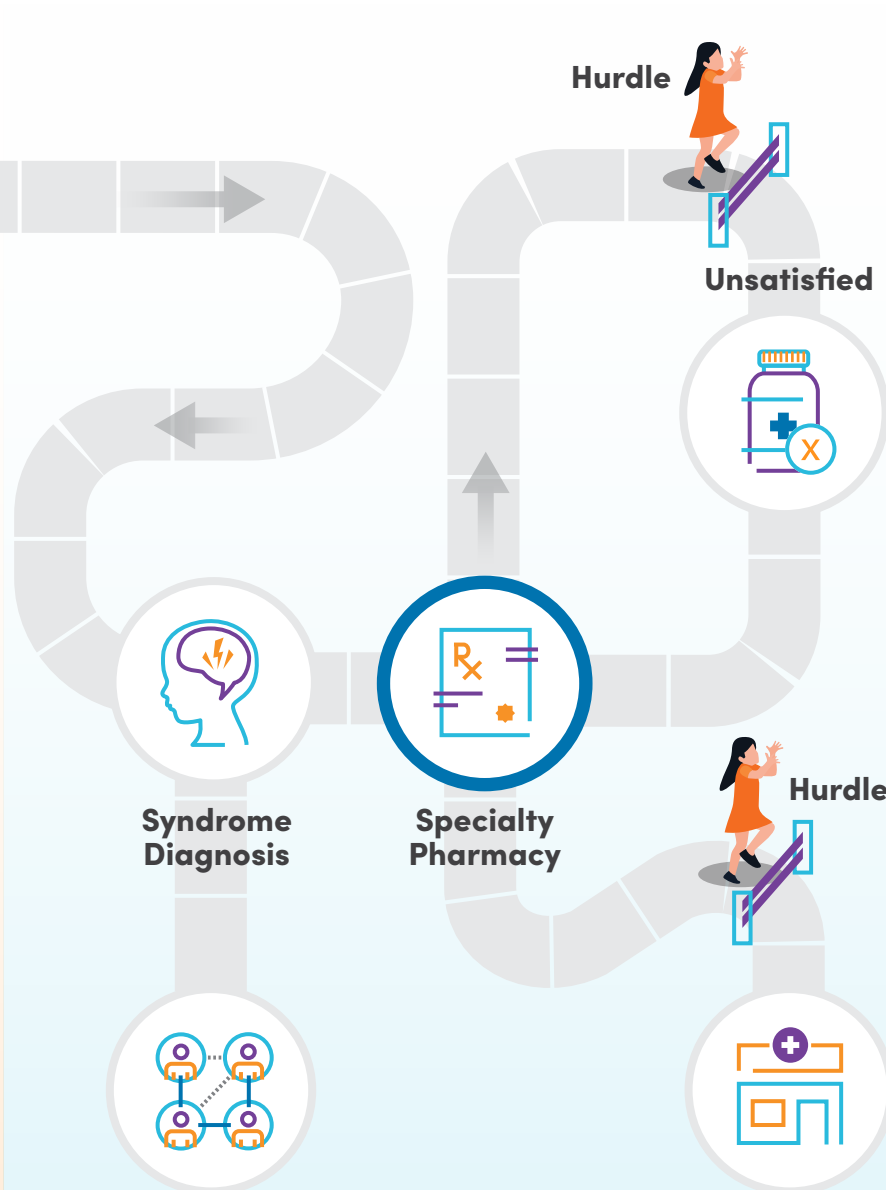
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As individuals and/or caregivers move through changing needs, many will be prescribed a specialty drug that will need to be filled at a specialty pharmacy.

Click here to learn more about Specialty Pharmacies +



Neurologists, Epileptologists, Multidisciplinary

Early Development & Symptom Onset

Health Plan

Retail Pharmacy

Specialists

Specialty Pharmacy

Insurance Providers

Complete Care Team

Adulthood and the Future

Initial Development

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What Is a Specialty Pharmacy Provider (SPP)?

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A **specialty pharmacy provider** is a licensed and accredited pharmacy that provides medications for people with serious health conditions requiring complex therapies, such as cancer, hepatitis, rheumatoid arthritis, HIV/AIDS, multiple sclerosis, cystic fibrosis, organ transplantation, hemophilia and other bleeding disorders, and rare diseases.¹

Specialty pharmacies are not like typical retail pharmacies and are usually not open to the public to walk in. Medications from a specialty pharmacy are shipped or delivered by a delivery service. It's important to know that ordering and refilling specialty medications takes additional time, which should be accounted for when refilling.



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Why Do I Need to Use a Specialty Pharmacy?

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Health plans and PBMs use a specialty pharmacy to better manage complex chronic conditions often treated with costly medications.

The decision to require a medication be dispensed through a specialty pharmacy is impacted by both the manufacturer and the health plan and/or PBM.



Hurdles:

- Providers are unaware of SPP requirement
- Individuals don't know which drugs require SPP dispensing
- Individuals don't know which SPP to use or how to find it
- Specialty pharmacies are not like retail, you typically cannot just walk into one



Insights:

Locating your SPP network and specialty drugs

- Contact your health plan or PBM using your healthcare insurance card to determine the preferred SPP
- Check your plan's online formulary through the patient portal
- Manufacturer HUB for prescribed drug can often provide support



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How Does a Specialty Pharmacy Prescription Get Filled?

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Prescriptions are typically transmitted electronically (electronic Rx) from a doctor's electronic medical record to the pharmacy directly.

SPP reaches out to the individual or caregiver through contact information provided on the Rx. First contact usually:

- Establishes disease/condition
- Walks through directions and side effects
- Provides any training needed to give the drug
- Talks about further contact from the SPP as follow-up calls
- Sets up delivery date and reimbursement with individual or caregiver



Hurdles:

- If the prescription is sent to a retail pharmacy that is unable to fill it
- If the prescription requires a prior authorization or some form of utilization management
- If there is significant financial impact to the individual (ie, out-of-pocket cost)



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What Happens When My Prescription Is Sent to the Wrong Pharmacy?

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Sent to retail pharmacy:

- Retail pharmacy gets notified that Rx must be filled at SPP but doesn't always tell members which SPP is in their network
- Electronic Rx's can get put on hold and don't get transferred to the appropriate SPP
- Individual often has to contact the provider's office and tell them where to resend the Rx
- Individual must find out which SPP is in their network and let the provider's office know where the Rx must be sent



Insights:

- Ask your retail pharmacy if the payer noted who your specialty pharmacy provider is
- Find out which SPP is allowed to fill your prescription
- Contact your provider office and let them know the Rx must be filled at an SPP and where they should resend the Rx
- You may also contact the SPP identified and let them know which retail pharmacy held the original Rx and have them transfer it into the SPP. This can be quicker than involving the provider's office



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What Does It Mean When My Prescription Requires a Prior Authorization?

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This means there are some things your health insurance company wants to confirm before approving the requested drug, such as:

- Individual's age
 - Previous therapy
 - Diagnosis
 - Safety concerns
 - Prescriber (specialist)
-
- PA can also include requirements to try another product before receiving the requested agent (step therapy) or limit the quantity an individual may receive (quantity limit)
 - If approved, an initial authorization period is assigned to the approval (usually 6-12 months). If denied, an individual may appeal



Insights:

- Some drugs also include reauthorization criteria, which mean conditions that must be met for individuals to continue therapy
- Your SPP will notify your provider that a PA is required and often helps the provider fill out the paperwork
- Make sure your provider has a full history of medications previously tried
- Your SPP will notify you (most often) when your PA has been approved. If it has been denied, TSC Alliance has resources that can help with appeals
- Your SPP will call to set up payment and delivery
- If it has been more than 72 hours, contact your SPP and your provider's office for the status of the PA request



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What If I Cannot Afford My Prescription?

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How much you owe for your prescription depends on many things:

- Type of health plan (high deductible)
- Deductible
- Formulary tier
- Cost of your medication



Insights:

- The SPP can help you locate financial assistance
- HUB by the pharmaceutical company for the prescribed drug can also help

Types of financial assistance:

- Copay/discount card (commercial members)
- Patient assistance program (income based)
 - SPP/HUB can assist with completion of paperwork
- Foundation's Medicare members may need to ask SPP if there are any programs available for the prescribed drug

Your Team and the Transition to Adulthood

Ashley Pounders
MSN, FNP-C
Director, Medical Affairs,
TSC Alliance

Julie Scroggins
Community Programs
Manager, West
TSC Alliance





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About the TSC Alliance

The TSC Alliance was founded in 1974 and is an internationally recognized nonprofit organization dedicated to finding a cure for TSC while improving the lives of those affected¹

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Goals

Accelerate
Research

Improve Access
and Quality of
Care

Support and
Empower
Constituents

Educate and
Mobilize to
Increase
Investment

Drug Therapy
Guidelines

Build and
Strengthen
Organization

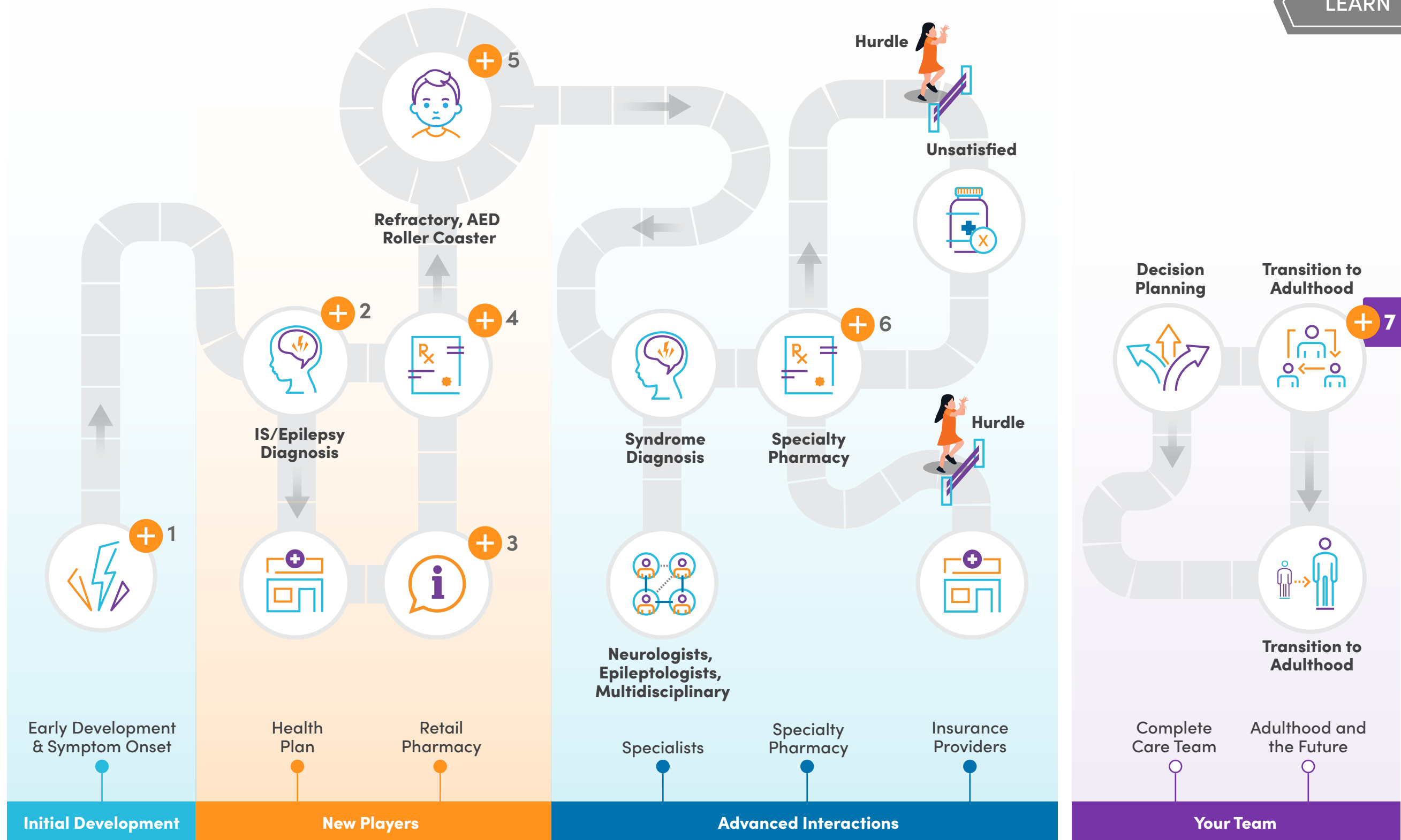


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Potential Hurdles in the TSC Journey

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Potential Hurdles in the TSC Journey

Click [here](#) to see insights

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What will happen as my child ages?

Will our new neuro be a good fit?

Will I be able to manage my child's medications?

The transition phase should start around the preteen years. Start having conversations with your current healthcare team regarding the process in your state regarding guardianship or conservatorship. This will require legal documentation.

Early Development & Symptom Onset

Health Plan

Retail Pharmacy

Specialists

Specialty Pharmacy

Insurance Providers

Complete Care Team

Adulthood and the Future

Initial Development

New Players

Advanced Interactions

Your Team

Hurdle

Unsatisfied

Decision Planning

Transition to Adulthood

Transition to Adulthood



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Potential Hurdles in the TSC Journey

Click [here](#) to read the key takeaways from this tool

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Key Takeaways

Click [here](#) to return to beginning

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- Health plans and PBMs make coverage decisions through committees comprised of practicing physicians, pharmacists, and nurses
- Specialty pharmacies are used to maximize clinical outcomes in complex chronic conditions¹
- Be PROACTIVE in understanding your pharmacy benefits and communicating with providers
- Know which drugs require SPP dispensing and what your specialty pharmacy is
- Individuals should track when authorizations will expire and keep enough drug on hand
- SPPs can help with affordability through various programs. Ask about available programs
- As adulthood approaches, supply appropriate documents in preteen years to reduce disruption
- The TSC Alliance has numerous resources available for members. Contact TSC Alliance Support Navigators with any questions or concerns

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Introducing



Current TSC Alliance Partnerships That Offer Resources

Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism (AGENDA): <https://www.allianceagenda.org/>

American Thoracic Society Public Advisory Roundtable (ATS PAR): <https://www.thoracic.org/patients/par/>

The Arc: <https://thearc.org/>

Child Neurology Foundation: <https://www.childneurologyfoundation.org/>

Epilepsy Leadership Council: <https://www.epilepsyleadershipcouncil.org/>

Global Genes: <https://globalgenes.org/>

Infantile Spasms Action Network (ISAN): <https://infantilespasms.org/>

National Organization for Rare Disorders (NORD): <https://rarediseases.org>

Rare Epilepsy Network: <https://www.rareepilepsynetwork.org/>

Seizure Action Plan (SAP) Coalition: <https://www.seizureactionplans.org/>



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Potential Hurdles in the TSC Journey

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TSC symptoms can present differently in every individual with TSC resulting in many drug therapies

Brain



- Anti-epileptic drugs (AEDs) for seizures¹
- Immunotherapies (mTOR inhibitors)^{2,3}

Kidneys



- Blood pressure agents⁴
- Low-protein diets⁴
- Immunotherapies (mTOR inhibitors)^{2,3}

Skin



- Topical treatments for skin conditions⁵

Lungs



- Immunotherapies for lung disease⁶

Heart



- Agents that reduce fluid buildup⁷
- Blood pressure agents⁷

mTOR = mechanistic target of rapamycin.

References: 1. TSC Alliance. Updated August 2016. Accessed April 3, 2020. <https://www.tsalliance.org/about-tsc/signs-and-symptoms-of-tsc/brain-and-neurological-function/epilepsy-and-seizure-disorders/> 2. MacKeigan JP, et al. *J Neurooncol*. 2015;17(12):1550-1559. doi:10.1093/neuonc/nov152 3. Zou Z, et al. *Cell Biosci*. 2020;10:31. doi:10.1186/s13578-020-00396-14. Massachusetts General Hospital. Accessed January 12, 2021. <https://www.massgeneral.org/neurology/tsc/patient-education/how-tsc-affects-kidneys> 5. TSC Alliance. Updated December 2013. Accessed November 14, 2019. <https://www.tsalliance.org/about-tsc/signs-and-symptoms-of-tsc/skin/> 6. TSC Alliance. Updated November 2013. Accessed January 13, 2021. <https://www.tsalliance.org/about-tsc/signs-and-symptoms-of-tsc/lungs> 7. Hinton RB, et al. *J Am Heart Assoc*. 2014;3(6):e001493. doi:10.1161/JAHA.114.001493

Early Development
& Symptom Onset

Initial Development

Health
Plan

Retail
Pharmacy

New Players

Specialists

Specialty
Pharmacy

Advanced Interactions

Insurance
Providers

Complete
Care Team

Adulthood and
the Future

Your Team



Common Jargon

Cost Sharing

| | |
|----------------|---|
| Deductible | The amount of money you must pay before insurance will pay a claim ¹ |
| Co-insurance | Your share against a claim ² |
| Copay | The amount you owe after insurance has paid ³ |
| Out of pocket | Money paid from your reserves ⁴ |
| Out of network | An HCP that doesn't have a contract with your health plan to provide service ⁴ |

Healthcare Services

| | |
|--------------------------|---|
| Pharmacy Benefit Manager | A third-party organization that administers prescription drug benefits on behalf of health plans ⁵ |
| Health plan | A type of insurance coverage that pays for medical and surgical expenses incurred by the insured ⁴ |
| Vertical integration | The combination of two or more stages of production normally operated by separate firms, such as when health plans acquire pharmacy benefit managers or specialty pharmacies ⁶ |
| Specialist consult | A conversation with a doctor that specializes in a disease or body system, such as a neurologist ⁴ |
| Genetic testing | Type of medical test that identifies changes in chromosomes, genes, or proteins and can confirm or rule out suspected genetic conditions ⁷ |

Pharmacy

| | |
|------------------|--|
| Formulary & Tier | A formulary is a list of prescription drugs covered by your health plan ⁴ A tier is a category within the formulary (usually by drug type) that further divides drugs by cost ⁴ |
| Electronic Rx | A prescription entered into a computer that is automatically sent to a pharmacy ⁸ |
| Side effects | An unwanted effect from a drug that comes along with the intended effect ⁴ |

References:1. HealthCare.gov. Deductible. Accessed January 12, 2021. <https://www.healthcare.gov/glossary/deductible/>2. HealthCare.gov. Coinsurance. Accessed January 12, 2021. <https://www.healthcare.gov/glossary/co-insurance/>3. HealthCare.gov. Copayment. Accessed January 12, 2021. <https://www.healthcare.gov/glossary/co-payment/>4. Centers for Medicare and Medicaid Services. Updated May 14, 2006. Accessed January 12, 2021. <https://www.cms.gov/apps/glossary/default.asp?Letter=O&Language=English>5. The Commonwealth Fund. April 22, 2019. Accessed January 12, 2021. <https://www.commonwealthfund.org/publications/explainer/2019/apr/pharmacy-benefit-managers-and-their-role-drug-spending>6. Hanna J. *Pharmacy Times*. Accessed January 26, 2021. <https://www.pharmacytimes.com/news/vertical-integration-in-health-care-the-next-stairway-to-heaven>7. National Library of Medicine. MedlinePlus. Genetics. Accessed July 14, 2021. <https://medlineplus.gov/genetics/understanding/testing/genetic-testing> 8. HealthIT.gov. Updated September 10, 2019. Accessed January 12, 2021. <https://www.healthit.gov/faq/what-electronic-prescribing>



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How Are Decisions Made?



Utilization Management Types

| | |
|--------------------------|---|
| Prior Authorization (PA) | Approval from a health plan that may be required before a service or prescription is covered by a health plan ¹ |
| Step Therapy | Type of prior authorization that requires use of the most preferred drug therapy before allowing other therapies ² |
| Quantity Limit | Limit on the amount of a drug per duration of time (eg, 30 pills per 30 days) ³ |
| Medical Policy | A set of guidelines or requirements that need to be met for medical services, procedures, devices, and drugs before coverage is provided ⁴ |
| Out of Network | An HCP that doesn't have a contract with your health plan to provide service ⁵ |

General Individual Cost Share

| | |
|---------------------|---|
| Tier 1 | Prescription drug tier with the lowest-cost tier of prescription drugs, majority are generic ^{6,7} |
| Tier 2 | Prescription drug tier with medium-cost drugs, most are generic with some brand-named drugs ^{6,7} |
| Tier 3 | Prescription drug tier with higher-cost drugs, the majority are brand-named drugs and some are specialty drugs ^{6,7} |
| Tier 4 or Specialty | Prescription drug tier with the highest-cost drugs, majority are specialty drugs ^{6,7} |
| Out of Network | An HCP that doesn't have a contract with your health plan to provide service ⁵ |

References: 1. HealthCare.gov. Prior authorization. Accessed January 12, 2021. <https://www.healthcare.gov/glossary/prior-authorization/> 2. Centers for Medicare and Medicaid Services. August 7, 2018. Accessed January 12, 2021. <https://www.cms.gov/newsroom/fact-sheets/medicare-advantage-prior-authorization-and-step-therapy-part-b-drugs> 3. Medicare Interactive.org. Accessed January 12, 2021. <https://www.medicareinteractive.org/glossary/quantity-limit> 4. Wellmark. Accessed January 12, 2021. <https://www.wellmark.com/Provider/MedPoliciesAndAuthorizations/MedicalPolicies/MedicalPolicies.aspx> 5. Blue Cross and Blue Shield of Illinois. 2021. Accessed July 13, 2021. <https://www.bcbsil.com/insurance-basics/understanding-health-insurance/glossary#O> 6. Blue Cross Blue Shield of North Carolina. 2021. Accessed January 12, 2021. <https://www.bluecrossnc.com/understanding-insurance/how-drug-benefits-work/copayment-tier-definitions#:~:text=Copayment%20Definitions%20for%20the%20Four,some%20brand%20Dname%20prescription%20drugs> 7. Blue Cross Blue Shield Blue Care Network of Michigan. Updated April 27, 2020. Accessed January 12, 2021. <https://www.bcbsm.com/medicare/help/understanding-plans/pharmacy-prescription-drugs/tiers.html>



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