Welcome to PANTHER RARE
IMPORTANT
INFORMATION
INSIDE

urac ACCREDITED
Specialty Pharmacy
Expires 05/01/2027

urac ACCREDITED
Rare Disease
Pharmacy Center of
Excellence
Expires 05/01/2027

NABP
Accredited
Digital Pharmacy

ACHC ACCREDITED
DISTINCTION IN
ORPHAN DRUGS

PATIENT CHOICE AWARD WINNER

PANTHERx® Rare Pharmacy services patients nationwide and is headquartered in Pittsburgh, Pennsylvania.

Our mission is to empower and champion individuals living with rare and devastating conditions, as the preferred pharmacy solution, by providing superior care and personalized support to all those invested in the patient journey.

We take pride in the differentiated level of care provided to our patients, and as a result, we consistently rank as a leader in patient satisfaction across all specialty pharmacies.

TABLE OF CONTENTS

Welcome	1
C.A.R.E. Launch	2
Continuum of Care	3
Notice of Privacy Practices	4
Patient Rights and Responsibilities	8
Frequently Asked Questions	10
Defining Rare Pharmacy	12
Accessing Additional Resources	13

Welcome to PANTHERx® Rare Pharmacy

PANTHERx is one of the nation's leading rare disease pharmacies. We provide high-touch clinical services while dispensing rare and traditional specialty medications for patients living with uniquely devastating diseases.

As a patient at PANTHERx, you'll find that we're more than just a pharmacy. Our team of dedicated pharmacists and nurses understand that managing a rare condition requires a higher level of care, attention, and coordination. We are here to help you through every step of your health journey.

What to Expect:

Monthly Adherence Calls

- The PANTHERx team will call you to introduce you or your caregiver to our services and provide introductory medication counseling.
- We will contact you monthly to assess how you are doing and refill your prescriptions to prevent a gap in therapy.

Patient Assistance Support

- Our experienced staff is readily available to locate necessary resources, including manufacturer programs and foundations, to minimize the financial burden of your medications.

24/7 Availability

- PANTHERx business hours are Monday-Friday 8am to 8pm, Saturday 9am to 3pm EST, but PANTHERx clinicians are on-call 24/7 to answer any questions you may have.

Complimentary Medication Delivery

- PANTHERx provides free shipping to your location of choice within the United States and it's territories.

For Patient Inquiries:

- If your request is received after normal business hours; clinical phone messages will be responded to within 1 hour and nonclinical phone messages and all emails will be responded to within 24 hours of receipt or the next business day.

121 Bayer Road, Building 5
Pittsburgh, PA 15205

PHONE: 855.726.8479
FAX: 855.246.3986

www.pantherxrare.com

We are here to serve you, our patient, and provide you with the care that you deserve.

It begins with me. It begins with

Compassion | Accountability | Respect | Excellence

OUR **MISSION**

To empower and champion individuals living with rare and devastating conditions, as the preferred pharmacy solution, by providing superior care and personalized support to all those invested in the patient journey.

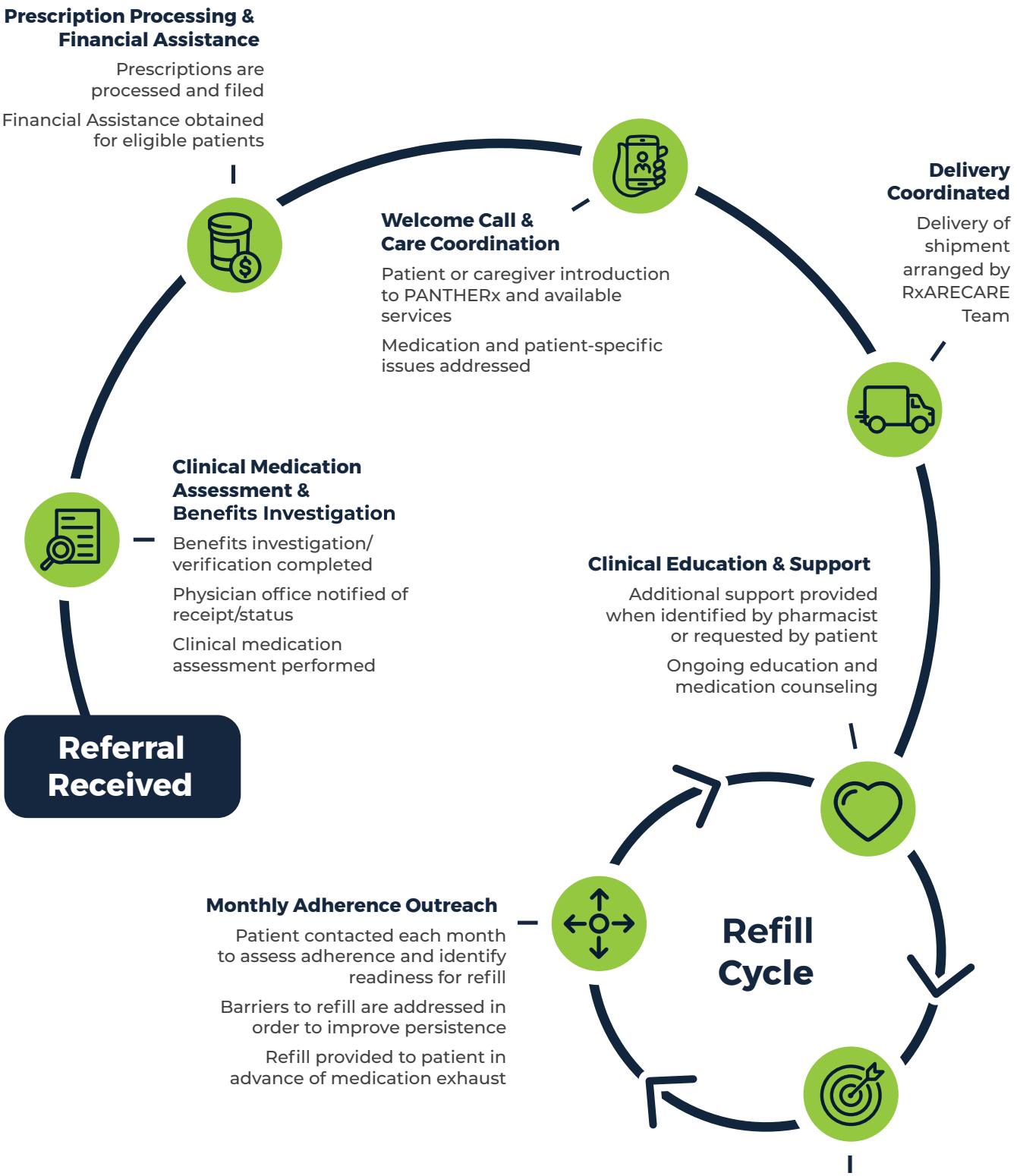
OUR **VISION**

PANTHERx Rare is setting the standard for the rare pharmacy industry by empowering individuals living with rare diseases to experience the moments in life most important to them by providing unrivaled comprehensive care to our patients, treatment support to our providers, and outcomes-driven service to our partners.

OUR **VALUES**

Offering compassion, hope, and support for every individual living with a rare disease.

PANTHERx RARE®



PANTHERx® Rare Pharmacy

Continuum of Care

Notice of Privacy Practices

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW THIS NOTICE CAREFULLY.

This Notice of Privacy Practices ("Notice") describes the privacy practices of PANTHERx® Specialty Pharmacy and its affiliates and subsidiaries. PANTHERx Specialty Pharmacy is required by law to maintain the privacy of Protected Health Information ("PHI") and to provide individuals with notice of our legal duties and privacy practices with respect to PHI. PHI is information that may identify you and that relates to your past, present or future physical or mental health or condition and related health care services. This Notice describes how we may use and disclose PHI about you and your rights regarding the use and disclosure of PHI. Your PHI may be stored electronically and may be disclosed electronically. We are required by law to notify affected individuals following a breach involving unsecured PHI.

We are required to abide by the terms of this Notice currently in effect. We reserve the right to revise or change this Notice and to make any such change applicable to all PHI that we maintain (including PHI obtained before the change). If we change our Notice, we will provide a copy of the revised Notice to you or your representative upon request. We will also post a copy of the current Notice at our pharmacy location(s) and on our Web site at www.pantherxrare.com. You may also obtain a copy of any revised Notice by contacting PANTHERx Specialty Pharmacy's Privacy Officer.

HOW WE MAY USE AND DISCLOSE MEDICAL INFORMATION ABOUT YOU: We may use and disclose your PHI as described below without your consent or authorization unless otherwise required by applicable law. Not every use or disclosure in a category will be listed. Your PHI may be stored in paper, electronic or other form and may be disclosed electronically and by other methods. We are required to comply with any state laws that impose stricter standards than the uses and disclosures described in this Notice.

1. **FOR TREATMENT:** We may use and disclose PHI about you to provide you with medical treatment, medications, or services and to coordinate your care. For example, we may disclose your PHI to hospitals, physicians, counselors, and any other entity involved in your care. We may use and disclose PHI to contact you by mail, e-mail, or phone to remind you that you have an upcoming prescription due for refill. We may use and disclose PHI to tell you about or recommend possible treatment options or alternatives that may be of interest to you.
2. **FOR PAYMENT:** We may use and disclose PHI about you so that the treatment and services you receive from us may be billed to and payment may be collected from you, an insurance company, or a third party. For example, we may provide information to your health insurance company so that the insurer will reimburse you or us, we may need to obtain prior approval from your insurer for care, and we may use and disclose your health information to determine whether you are eligible for health benefits.
3. **FOR HEALTH CARE OPERATIONS:** We may use and disclose PHI about you for health care operations purposes, including proper administration of records, evaluation of quality of treatment, assessing the care and outcome of your case and others like it, arranging for legal services, and providing appointment reminders. For example, we may use PHI to evaluate the performance of our staff. We also may make disclosures of limited PHI incidental to permitted disclosures.
4. **FAMILY MEMBERS/DISASTER NOTIFICATION:** Unless you object, we may disclose PHI to a family member or other individual who is involved in your medical care or payment for your care. In addition, we may disclose PHI about you to an entity assisting in a disaster relief effort so that your family can be notified about your condition, status, and location.
5. **AS REQUIRED BY LAW:** We may use and disclose your PHI when required to do so by federal, state or local law.
6. **TO AVERT A SERIOUS THREAT TO HEALTH OR SAFETY:** We may use and disclose your PHI if we, in good faith, believe that such disclosure is necessary to prevent or lessen a serious and imminent threat to the health and safety of you, the public, or another person.
7. **TO BUSINESS ASSOCIATES:** We may disclose your PHI to third parties known as "Business Associates" that perform various activities (e.g. legal services, delivery of goods) for us and that agree to protect the privacy of your PHI.
8. **FOR SPECIFIED GOVERNMENT FUNCTIONS:** In certain circumstances, we may use and disclose your PHI for specialized government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations, and inmates or law enforcement custody.
9. **FOR WORKERS' COMPENSATION:** We may disclose your PHI for workers' compensation or similar programs.
10. **FOR PUBLIC HEALTH ACTIVITIES:** We may use and disclose PHI about you for public health activities as authorized by law, such as disclosures to prevent or control disease, injury or disability, to report reactions to medications or problems with products, to provide notices of recalls of products, and to report vital statistics, disease information, and similar information to public health authorities.
11. **TO REPORT ABUSE, NEGLECT OR DOMESTIC VIOLENCE:** As authorized by law, we may disclose PHI to government authorities if we believe an individual is the victim of abuse, neglect, or domestic violence and certain conditions are met.
12. **FOR HEALTH OVERSIGHT ACTIVITIES:** We may disclose PHI to a health oversight agency, such as the Department of Health and Human Services, for activities authorized by law. These oversight activities include audits, investigations, inspections, and licensure. These activities are necessary for the government to monitor the health care system, government programs, and compliance with civil rights laws.
13. **IN CONNECTION WITH LAWSUITS AND ADMINISTRATIVE PROCEEDINGS:** We may use and disclose your PHI in response to an order of a court or administrative tribunal. We may also use and disclose your PHI in response to a subpoena, discovery request, or other lawful process, but only when reasonable efforts have been made to notify you about the request or to obtain an order protecting your PHI.
14. **TO LAW ENFORCEMENT:** As authorized by law, we may disclose your PHI to law enforcement officials for certain law enforcement purposes.

15. **TO CORONERS, MEDICAL EXAMINERS, OR FUNERAL DIRECTORS:** We may disclose PHI to coroners, medical examiners, or funeral directors, as authorized by law, prior to and in reasonable anticipation of an individual's death.
16. **FOR RESEARCH:** We may, under select circumstances, use and disclose your PHI for research.
17. **FOR ORGAN, EYE OR TISSUE DONATION:** We may use and disclose your PHI to organ procurement organizations or other entities engaged in the procurement, banking, or transplantation of organs, eyes, or tissue for the purpose of facilitating the donation and transplantation.
18. **LIMITED DATA:** We may remove most information that identifies you from a set of data and use and disclose this data set for research, public health and health care operations, provided the recipients of the data set agree to keep it confidential.
19. **HEALTH INFORMATION EXCHANGES:** We may participate in one or more Health Information Exchanges (HIEs) and may electronically share your PHI for treatment, payment, healthcare operations and other permitted purposes with other participants in the HIE. HIEs allow your health care providers to efficiently access and use your PHI as necessary for treatment and other lawful purposes.

AUTHORIZATION TO USE OR DISCLOSE PHI: Other uses and disclosures of PHI not described above in this Notice will be made only with a written authorization signed by you or your representative. Subject to compliance with limited exceptions, we will not use or disclose psychotherapy notes, use or disclose your PHI for marketing purposes, or sell your PHI unless you have signed an authorization. If you or your representative authorizes us to use or disclose your PHI, you may revoke that authorization in writing at any time to stop future uses or disclosures. However, your decision to revoke the authorization will not affect or undo any use or disclosure of your PHI that occurred before you notified us of your decision to revoke your authorization.

YOUR RIGHTS REGARDING PHI: You have the following rights regarding PHI we maintain about you. If you have given another individual a medical power of attorney, if another individual is appointed as your legal guardian or if another individual is authorized by law to make health care decisions for you (known as a "personal representative"), that individual may exercise any of the following rights listed below. Please contact the Privacy Officer at the address listed below to obtain the appropriate form to exercise these rights.

1. **RIGHT TO INSPECT AND COPY:** You have the right to inspect and obtain a copy of your PHI that we maintain or direct us to send a copy of your PHI to another person designated by you in writing. In most cases, we will provide this access to you or the person you designate within 30 days of your request. This right applies to PHI used to make decisions about you or payment for your care, subject to limited exceptions. We may charge a reasonable fee for the costs of copying, mailing, and/or other supplies associated with your request. If your PHI is stored electronically and you request an electronic copy, we will provide it to you in a readable electronic format.
2. **RIGHT TO REQUEST AN AMENDMENT:** You have the right to request that we amend our records if you believe that your PHI is incorrect or incomplete. We may deny the request if it is not in writing or does not include a reason for the amendment. We may deny the request for certain other reasons, including that the records are accurate and complete. Requests must be made in writing.
3. **RIGHT TO AN ACCOUNTING:** You have the right to request a list of disclosures of your PHI made by us for certain reasons, including disclosures related to public purposes authorized by law and certain research disclosures. The list will not include disclosures that we are not required to record such as disclosures you authorize. We will provide the first accounting you request during any 12-month period without charge. Additional accounting requests made during the same 12-month period may be subject to a reasonable cost-based fee.
4. **RIGHT TO REQUEST RESTRICTIONS:** You may request restrictions on certain uses and disclosure of your PHI. However, we are not required to agree to your request, except for requests to restrict disclosures to a health plan when you have paid in full out- of-pocket for your care and when the disclosures are not required by law. If we do agree, we will comply with your request unless the information is needed to provide you emergency treatment.

5. **RIGHT TO RECEIVE CONFIDENTIAL COMMUNICATIONS:** You have the right to request that we communicate with you through alternative means or locations. We will not request that you provide any reasons for your request and will accommodate your reasonable requests. We may require you to provide information on how payment will be handled and an address or other method to reach you. Requests must be made in writing.
6. **RIGHT TO RECEIVE A PAPER COPY OF THIS NOTICE:** You have the right to a paper copy of this Notice at any time even if you have received this Notice previously electronically. You may obtain a copy by contacting the Privacy Officer or by visiting www.pantherxrare.com.

TO REPORT A CONCERN: If you believe your privacy rights have been violated, you may file a complaint with us or with the Secretary of the Federal Department of Health and Human Services. To file a complaint with us, submit your complaint in writing to our Privacy Officer. You will not be penalized for filing a complaint.

CONTACT PERSON: You may also contact our Privacy Officer if you have questions or comments about our privacy practices or wish to exercise any of your rights described in this Notice. You can reach our Privacy Officer at the following address:

PANTHERx Specialty Pharmacy
Attn: Privacy Officer
121 Bayer Road, Building 5
Pittsburgh, PA 15205

Toll-Free: 855-726-8479
Fax: 855-246-3986

Effective Date of this Notice: 8/1/2019

Patient Rights

You have the right to be fully informed in advance about care/service to be provided, including the disciplines that furnish care and the frequency of visits, as well as any modifications to the plan of care

You have the right to know about the philosophy and characteristics of the patient management program

You have the right to be informed, both orally and in writing, in advance of care being provided, of the charges, including payment for care/service expected from third parties, and any charges for which the client/patient will be responsible

You have the right to get important information about your care appropriate to your age, understanding, and language (If you have vision, speech, hearing, and/or other impairments, we can provide support to ensure your needs are met)

You have the right to receive information about the scope of services that the organization will provide and specific limitations on those services either verbally or in writing

You have the right to receive administrative information regarding changes in or termination of the patient management program

You have the right to participate in the development and periodic revision of the plan of care

You have the right to refuse care or treatment after the consequences of refusing care or treatment are fully presented

You have the right to be informed of client/patient rights under state law to formulate an Advanced Directive, if applicable

You have the right to have your property and person treated with respect, consideration, and recognition of client/patient dignity and individualitywithout discrimination based on race, color, religion, national origin, sex, age, disability, retaliation, genetic information, harassment, pregnancy, or sexual harassment

You have the right to be able to identify visiting personnel members through proper identification

You have the right to be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source and misappropriation of client/patient property

You have the right to communicate grievances/complaints to PANTHERx regarding treatment or care that is (or fails to be) furnished

You have the right to confidentiality and privacy of all information contained in the client/patient record and of Protected Health Information

You have the right to have personal health information shared with the patient management program only in accordance with state and federal law

You have the right to be advised on agency's policies and procedures regarding the disclosure of clinical records

You have the right to choose a health care provider, including choosing an attending physician, if applicable

You have the right to receive appropriate care without discrimination in accordance with physician orders, if applicable

You have the right to be informed of any financial benefits when referred to an organization

You have the right to be fully informed of one's responsibilities

You have the right to speak with a health professional

You have the right to identify the staff member of the program and their job title, and to speak with a supervisor of the staff member if requested

You have the right to decline participation, revoke consent, or disenrollment at any point in time

Patient Responsibilities

You are responsible for providing as much information about your health and medical history as possible, including your other medications, vitamins, supplements, and allergies

You are responsible for submitting any form that is necessary to participate in the program, to the extent required by law

You are responsible for asking questions, especially if you do not understand or need more information

You should treat our staff with courtesy and respect

You are responsible for giving accurate clinical and contact information and to notify the patient management program of changes in this information

You should actively participate in your care and follow the instructions for taking medication as directed

You are responsible for notifying your treating provider of your participation in the patient management program, if applicable

You are responsible for meeting your financial responsibility

You are responsible for communicating side effects to your pharmacist or prescriber right away

You are responsible for storing your medications appropriately

You are responsible for disposing unused medication in a safe method (our pharmacists can provide instructions for disposal if necessary)

Frequently Asked Questions

What is a rare pharmacy?

A rare pharmacy provides lifesaving medications and credentialed services to patients facing rare and devastating conditions. These therapies are often costly and require added expertise in order to ensure optimal outcomes. Just as you see a specialized doctor to treat your chronic condition, your rare pharmacists are trained to specialize in these therapies.

Why can't I have these prescriptions filled at my local pharmacy?

Orphan medications require special attention – especially from your pharmacist. Rare pharmacists are trained in these complex chronic conditions and know how to best manage your care, from dosing, to side-effect management and more. That's why we offer 24/7 access to our team: to make sure that you receive the care you deserve.

What is the PANTHERx Patient Management Program?

The PANTHERx Patient Management Program is included at no cost to you and you are automatically enrolled as a patient of PANTHERx. You may opt out at any time by notifying a PANTHERx representative either verbally or in writing.

The benefits of this program include managing side effects, improved overall health, increased disease and medication education and awareness, increased medication compliance, and coordination of care with your physician when necessary.

Can I get all of my prescriptions through PANTHERx?

Our focus is to make sure that you receive the medications necessary to manage your chronic rare conditions. We recommend that you continue to utilize your local pharmacy for other non-specialty medications. We do request that you inform us of any changes to medications filled elsewhere, as they may potentially interact with your rare medications.

How will I receive my medications from PANTHERx?

Our team will reach out to you each month to see how you are feeling and set up your next delivery of medications.

We use experienced carriers such as FedEx – at no additional cost to you – to ensure your medications are carefully shipped, and have designed our own "final mile" program to ensure you receive your shipment as promised.

How can I pay for my medications?

We accept check-by-phone, money orders and major credit cards, including: Visa, MasterCard, Discover and American Express. You may also request to be invoiced as part of your monthly shipment.

Since the out-of-pocket expense for these medications can be high, our team will work with you to ensure you have access to the care that is prescribed. Financial assistance programs are available and we can help you to enroll to offset the cost of your treatments.

What are your customer service hours?

Our team of pharmacists is available 24/7 at 855-PANTHRX (855-726-8479) or at www.pantherxrare.com.

How can I fill prescriptions through PANTHERx?

Call us today at 855-PANTHRX (855-726-8479). Our team will coordinate with your doctor's office and reach out to you to set up your shipment.

Who owns PANTHERx?

PANTHERx is owned by a leading investor consortium consisting of Nautic Partners, The Vistria Group, and General Atlantic.

What if PANTHERx is 'Out of Network' with my insurance provider?

There may be instances where PANTHERx is not considered 'in network' with your insurance provider. If that is found to be the case, we will try to work with your insurance to provide the medication to you or will coordinate with you and your prescriber to transfer the prescription to a pharmacy that is in network with your insurance.

What if I want a prescription substitution?

If you would like information on substituting your prescription medication for a different brand or generic, please reach out to your prescribing physician or feel free to contact a PANTHERx pharmacist to determine if there is a substitution available.

What if I want another pharmacy to fill my prescription?

If you would like to transfer your prescription to another pharmacy, please contact PANTHERx at 855-PANTHRx (855.726.8479) to determine what pharmacies are able to fill your medication. Some medications can only be filled at PANTHERx or are only available at certain pharmacies. We will be happy to assist with the transfer process if possible.

What if PANTHERx cannot fill my medication?

If your prescription is not available to be filled at PANTHERx we will work with you and your prescriber to transfer the prescription to a pharmacy that can meet your needs.

What if my medication is recalled?

PANTHERx will contact you in the event that medication we dispense to you has been recalled. Please be sure to keep your contact information up to date so you can be reached in a timely fashion. If you have any questions about a recall, feel free to call PANTHERx.

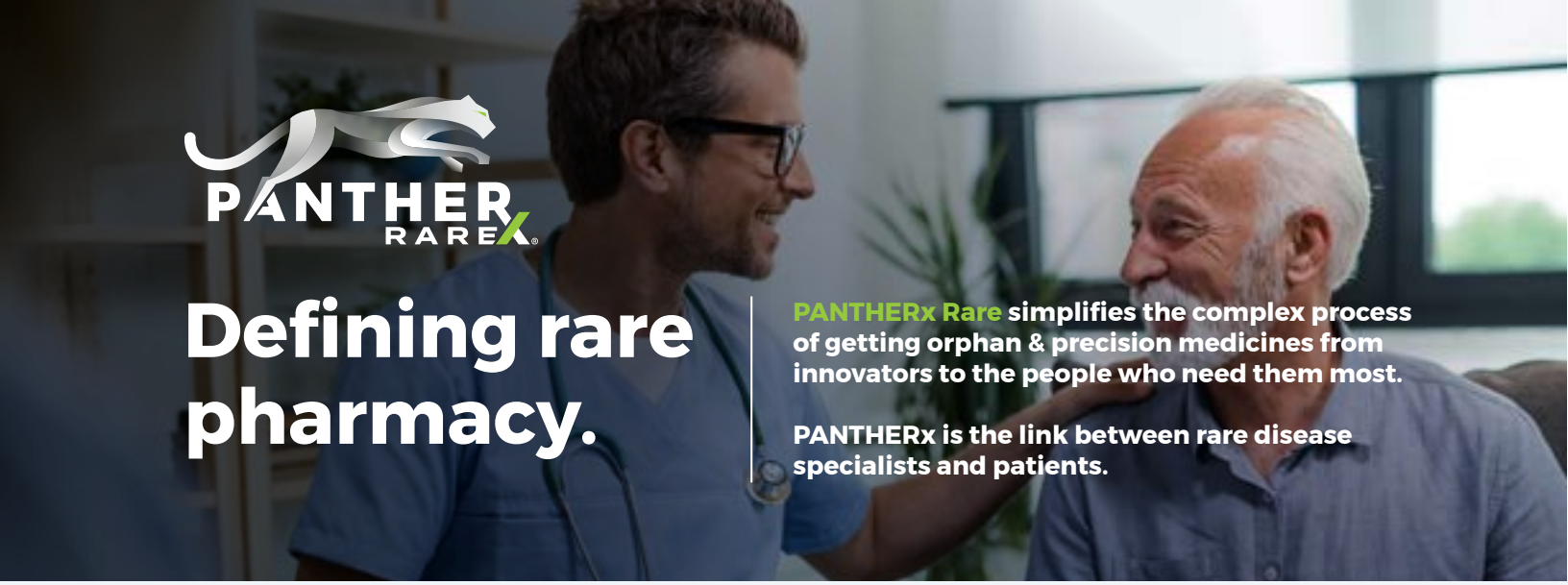
What if I experience a side effect?

If you feel you are experiencing a side effect or adverse reaction, please call your PANTHERx pharmacist or your prescriber. If the event is serious or life threatening, please go to the nearest emergency room or call 911.

How do I report concerns to PANTHERx?

If you wish to contact PANTHERx to report a concern or service issue, please contact PANTHERx at 855-PANTHRx (855.726.8479) to speak to our pharmacists. If you would rather send the information to PANTHERx, a Patient Concerns/Grievance form is located on our website. The form can be submitted via fax or mail. You will be contacted within two business days from the receipt of the form to address and resolve the concern. As a partner in your care, PANTHERx team works diligently to provide the highest level service to you or your family member.

https://pantherxrare.com/wp-content/uploads/2024/09/pantherxPatientConcernsGrievancesForm_DIGITAL-1.pdf



Defining rare pharmacy.

PANTHERx Rare simplifies the complex process of getting orphan & precision medicines from innovators to the people who need them most.

PANTHERx is the link between rare disease specialists and patients.

Our Support Services

- Personal White Glove Service
- Prescription Coordination & Fulfillment
- 24/7 Access To Your RxARECARE Pharmacist
- Prior Authorization Facilitation
- Adherence Education
- Therapy Welcome Kits
- Financial Assistance Program Enrollment
- Free Prescription Delivery
- Refill Reminders
- Innovative Technology To Empower You Along Your Journey

Accessing Additional Resources

Please visit
https://pantherxrare.com/wp-content/uploads/2025/03/Panther_book_031325_WebFile.pdf
to access a digital copy of this Welcome Kit Booklet and additional resources such as:

- **Drug Specific Materials**
- **PANTHERx Profile Patient Videos**
- **PRx Connect Rare Disease Community/ Patient Support Links**
- **& much more!**

For questions regarding this information, please contact us at 855-726-8479 or pharmacist@pantherxrare.com

If your request is received after normal business hours; clinical phone messages will be responded to within 1 hour and non-clinical phone messages and all emails will be responded to within 24 hours of receipt or the next business day.

Corporate Headquarters:

121 Bayer Road
Building 5
Pittsburgh, PA 15205

PHONE: 855.726.8479
FAX: 855.246.3986

Pharmacy Locations:

1120 Stevenson Mill Road, Suite 400
Coraopolis, PA 15108

6715 Tippecanoe Road, Suite C1
Canfield, Ohio 44406

280 Moore Lane
Collierville, TN 38017

www.pantherxrare.com

Centers for Medicare and Medicaid Supplier Standards

The products and/or services provided to you by PANTHERx Specialty Pharmacy are subject to the supplier standards contained in the federal regulations shown at 42 Code of Federal Regulations Section 424.57(c). These standards concern business professional and operational matters (e.g., honoring warranties and hours of operation). The full text of these standards can be obtained at https://www.ecfr.gov/current/title-42/part-424/section-424.57#p-424.57(c). Upon request we will furnish you a written copy of the standards.

PANTHERx RARE®

PANTHERx Rare Pharmacy; PANTHERx Specialty Pharmacy; Defining Rare Pharmacy; and Reinventing Specialty, Revolutionizing Pharmacy, Redefining Care are registered service marks of PANTHERx Specialty, LLC

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