FOR IMMEDIATE RELEASE
From: Plasma Protein Therapeutics Association (PPTA)

Patient Notification System (PNS): Be the first to know!
Confidential notification of plasma protein therapy withdrawals and recalls

The name says it all! The Patient Notification System notifies the patient directly of a voluntary and/or mandated recall of plasma protein therapies. This makes all the difference - while other notification systems are designed to inform physicians and pharmacists, the PNS empowers the patient to receive this important information directly via email, telephone or fax. There is no charge to register.

Register today at: www.patientnotificationsystem.org

About the PNS
Over a decade ago, the Plasma Protein Therapeutics Association (PPTA) and its members, working in collaboration with consumer organizations, developed this first-of-its-kind Patient Notification System (PNS).

- Easily accessible, comprehensive, and up-to-date information about all brands of immune globulins, blood clotting factors, alpha-1 proteinase inhibitors and other lifesaving plasma protein therapies.

- Confidential: all registrants; patients, physicians, family members, nurses, or pharmacists, are guaranteed that their information is never shared nor is it accessible by anyone other than the third-party company that houses the computers to run the system and send the notifications.

Ensuring Confidentiality
Maintaining patient confidentiality was a major consideration when developing the system. A working group comprised of stakeholders, including: U.S. Food and Drug Administration, Alpha-1 Association, Alpha-1 Foundation, Committee of Ten Thousand, Hemophilia Federation of America, Immune Deficiency Foundation and National Hemophilia Foundation, helped to design the system to safeguard sensitive registrant information. To ensure confidentiality, the PNS is operated by Stericycle, Inc., an independent organization that specializes in informing the public of pharmaceutical withdrawals and recalls (notifications). All registrant information is kept strictly confidential.

How to Register

1. Visit www.patientnotificationsystem.org or call the toll-free number, 1-888-UPDATE-U (1-888-873-2838). When you sign up, some basic contact information will be required, such as your name, address, email and phone number. You will set up your own password.

2. Choose your notification preference. During the registration process, you will be asked to select your “primary” method of notification. Registrants currently have the option of being notified by email, telephone or fax. We think you’ll agree that email is a great choice for your “primary” method of notification because it is instantaneous and it is accessible anywhere, even if a registrant is traveling. It is very important for patients to receive this information about recalls or withdrawals; don’t delay in registering and consider email as your “primary” choice for how to be notified. Your primary notification is always followed up by a duplicate notification sent via U.S. mail.

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3. Choose the therapies about which you would like to receive notification. Choose “other” if you are unsure of what medicine you are taking or you wish to receive all notifications.

4. Once you submit the required information, you will receive a confirmation and unique identification number. You will need this number and your password to access the system.

PNS in Action
If a therapy is withdrawn or recalled, the company involved immediately contacts Stericycle, Inc., which then notifies the registrant. Every effort is made to notify registrants within 24 hours. Registrants are notified twice. First, you will receive a notification from Stericycle via your designated “primary” notification method. Second, you will receive a U.S. mail letter containing the same information. The redundancy of two types of notification is intended to ensure that you receive your notification and are aware before you infuse or inject your therapy that there has not been an event. “Event” is the term that is used for a recall or a withdrawal.

Consumers also can go online to www.patientnotificationsystem.org or call a 24-hour, toll-free number 1-888-UPDATE-U (1-888-873-2838) for current information on product recalls or withdrawals. To maximize the usefulness of the system, it is important for consumers to keep accurate infusion logs and record the lot number, therapy and manufacturer for all therapies they use. Infusion logs are available by calling the toll-free number.

PPTA’s Role
The system is administered by the Plasma Protein Therapeutics Association (PPTA). The PNS is a comprehensive web-based system that is funded by manufacturers including: Baxter BioScience, Bayer Healthcare LLC, Biotest Pharmaceuticals Corporation, Cangene Corporation, CSL Behring, Grifols USA, Kedrion Biopharma, NovoNordisk Pharmaceuticals, Octapharma, and Pfizer.

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