

Voices to Practice

Patient and Family Insights for Blood Clot Awareness and Safer Women's Health Decisions

SIX PRIORITIES

01

Usable risk information

04

Symptom recognition and response

02

Individualized decisions

05

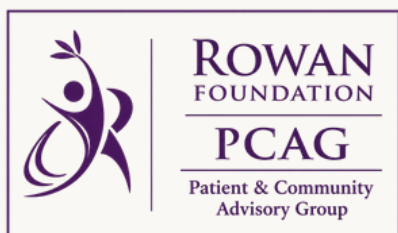
Patient voice

03

Hormonal and nonhormonal options

06

Credible information



OCTOBER 2026

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Executive summary

Blood clots are a serious and potentially life-threatening women's health concern. Risk may arise in connection with hormonal birth control, fertility treatment, pregnancy and the period after birth, certain forms of menopause hormone therapy, inherited or acquired clotting conditions, and other health or lifestyle factors.

Risk is not uniform across these settings or even within them. It varies by the specific treatment or condition, the individual, and the presence of other risk factors. It may also change over time. Yet women do not always receive information they can apply to their decisions, symptoms, and care.

Voices to Practice draws on two in-depth discussions with the Rowan Foundation Patient & Community Advisory Group (PCAG). Members brought varied experiences with blood clots, women's healthcare, recovery, caregiving, and loss. They included survivors, people continuing to live with the effects of blood clots, and families who lost daughters following clots associated with combined hormonal contraception.

Their perspectives point to a consistent need across women's health: clear, current, and individualized information that supports informed choice, symptom recognition, and appropriate care. The report identifies six priorities:

1. **Turn risk information into usable knowledge.** Women need relevant context, warning signs, and clear guidance about what to do.
2. **Make individualized decision-making the standard.** Health history, life stage, treatment goals, and personal preferences should inform women's health decisions.
3. **Give hormonal and nonhormonal options a fair hearing.** Balanced information should support informed contraceptive choice without dismissing patients' questions or preferences.
4. **Improve recognition and response when symptoms emerge.** Blood clots should remain a meaningful clinical consideration when symptoms, medications, and risk factors point in that direction.
5. **Build patient voice into safer care.** Listening can strengthen assessment and decision-making, but patients should not be expected to diagnose themselves.
6. **Put credible information within reach.** Medically reviewed resources should be clear, current, and available where women seek answers.

The report does not promote one choice for every woman. It calls for information and care that women can understand, evaluate, and use before a possible risk becomes a crisis.

About the PCAG and this report

The Rowan Foundation established the Patient & Community Advisory Group to ensure that its women's health and blood clot work is informed by people directly affected. The group includes blood clot survivors, people navigating recovery and continuing health decisions, family members, and bereaved parents.

This report reflects two in-depth, facilitated PCAG discussions held in 2026. Members were invited to speak candidly about what they wished had been clearer, what helped, where conversations or care fell short, and what could better prepare women and families in the future. The format allowed participants to explore their experiences in detail, respond to one another, and identify concerns that extended beyond any single account. Their perspectives were reviewed for recurring themes and considered alongside selected medical, public-health, and health-communication literature.

The work builds on the Foundation's 2025 Informed Choices: Improving Contraceptive Outcomes for Women roundtable. That discussion brought together professional perspectives on contraception, clotting risk, and informed decision-making. Voices to Practice adds a more focused lived-experience view: what women and families remember, what they needed, and what they believe deserves closer attention and application in the clinical setting or by medical care teams.

Why patient and family experience matters

Clinical evidence establishes what is known about risk, diagnosis, treatment, and outcomes. Patient and family experience reveals something different: how information is received, whether a warning is understood, what it is like to seek help while symptoms are unfolding, and where a healthcare process may look very different from the other side.

These experiences are not interchangeable. Some PCAG members described clear explanations, careful listening, and timely action. Others described information or communication gaps at moments when clarity and urgency mattered deeply. The report does not flatten those accounts into a single patient story. Their value lies in their range, and in the patterns that appear across them.

Lived experience cannot establish clinical guidance or predict what will happen to another person. It can identify questions worth asking, assumptions worth examining, and opportunities to make information and care more useful. That is the role it plays here.

Patient voice is not a single voice

No single person can speak for the full clotting community. Experiences differ by age, race and ethnicity, health history, life stage, access to care, reason for treatment, diagnosis, recovery, and outcome. Survivors, caregivers, and bereaved families may also see the same issues from very different perspectives. Each voice has value, but no individual experience should be treated as the definitive patient experience.

This is a central strength of the PCAG. It brings different voices into the same conversation, allowing the Foundation to identify shared concerns while respecting important differences. The Rowan Foundation intends to continue expanding the group and incorporating a broader range of experiences over time. Patient-informed work is strongest when it is shaped by a community of voices rather than being owned or defined by any one person.

Patient voice is not a single voice. Credible patient-informed work must make room for many experiences and perspectives.

01 Turn risk information into usable knowledge

Risk disclosure is not the same as risk understanding. Telling a patient that a complication is possible may satisfy the need to mention it. It does not necessarily prepare her to make a decision, recognize a warning sign, or act when something changes.

PCAG members described receiving clot-risk information in very different ways. Some did not recall a meaningful discussion when hormonal birth control was prescribed. Others knew that blood clots were possible but did not understand how symptoms might present or why the risk could apply to them. Young and otherwise healthy women may be especially unlikely to see themselves as potential blood clot patients. That makes clear, relevant counseling more important, not less.

Research about risk communication supports the need for information people can understand and use. How risk is framed affects comprehension. Absolute numbers, plain language, and carefully chosen visual formats can help, although no single approach will work for every person or every decision.^{1,2}

The goal is not to create fear. It is to make sure reassurance does not come at the expense of preparation.

A risk warning should do more than inform. It should prepare.

Words matter: “Rare” can obscure the seriousness of risk

The word “rare” may accurately describe how often an event occurs across a population. Accuracy matters. So does the way that accuracy is communicated.

For PCAG members, particularly parents who have lost daughters, the word can feel diminishing or dismissive. When a rare event changes or ends a life, its statistical frequency does not lessen the outcome. A family living with that loss does not experience it as a fraction of a percentage point. A survivor facing a long recovery does not feel less affected because most people will never share her experience.

This does not mean the word should never be used. It means “rare” should not be used as a conclusion. Frequency is only one part of informed decision-making. Patients also need to understand the seriousness of the possible outcome, the factors that may change their risk, the symptoms that require attention, and the options available to them.

“Rare” describes frequency. It does not describe significance, and it should never diminish a life changed or lost.

Risk can be communicated accurately without making affected patients and families feel that they do not count.

Birth control and clotting risk

Birth control is central to the Rowan Foundation's mission and to this report. Several PCAG families lost daughters following blood clots associated with combined hormonal contraception. Their experiences give urgency to a basic expectation: before a prescription is written, women should receive clear and individualized information about benefits, clotting risk, warning signs, and medically appropriate alternatives.



Patient-centered contraceptive counseling brings clinical knowledge together with the patient's goals, preferences, personal health history, and concerns.

The American College of Obstetricians and Gynecologists (ACOG) supports shared decision-making, patient autonomy, and balanced information about available options.³ Those principles matter because there is no single "right" method for every woman.

The reason for treatment also shapes the decision.

Hormonal birth control may be prescribed to prevent pregnancy or to address acne, polyendocrine metabolic ovarian syndrome (PMOS), formerly known as polycystic ovary syndrome (PCOS),⁴ heavy bleeding, painful periods, and other women's health concerns. A patient considering medication for acne may weigh benefits, risks, and alternatives differently from someone seeking contraception. A woman managing PMOS may have a different set of priorities still. The same prescription can serve different purposes; the counseling should reflect that.

This is not an argument against hormonal contraception. It is an argument for decisions that are fully informed, medically sound, and responsive to the individual.

Personal health history, clotting risk, treatment goals, and patient preferences all belong in a birth control decision.

Family health history and inherited risk

Family health history can provide important context, but it is not a complete safety measure. Many people do not know their full family history. Some families have little access to medical records or do not discuss health conditions openly. Inherited clotting disorders, such as factor V Leiden, may not be discovered until after a blood clot occurs. An unknown or negative family history therefore cannot be treated as proof that inherited risk is absent.

Family history can inform risk. An unknown family history cannot rule it out, and testing decisions deserve an honest, individualized discussion.

At the same time, routine thrombophilia testing is not recommended for everyone. American Society of Hematology guidance recommends against testing the general population before combined oral contraceptives are started and limits testing to specific clinical situations. The reasons include the low likelihood that broad screening will change care, the limits of what results can predict, cost, and the possibility of confusing or unintended consequences.⁵ That guidance should be stated plainly. It should not end the conversation. Patient-centered care leaves room for an individualized discussion when personal or family history, a known familial thrombophilia, prior clotting events, or patient concerns make testing relevant. Women should understand why testing may or may not be recommended, what a result could clarify, what it cannot predict, and whether it would change the decision at hand.

02 Make individualized decision-making the standard across women's health

Women encounter questions about hormones and clotting risk across their lives. Birth control, treatment for acne or PMOS, fertility treatment and IVF, pregnancy, the postpartum period, perimenopause, and menopause involve different benefits, different risks, and different personal priorities. They should not be collapsed into a single message that hormones are either safe or dangerous.

The stronger standard is informed choice: current and balanced information, attention to individual circumstances, and consultation with a qualified healthcare professional or medical care team. Informed choice does not require every patient to make the same decision. It requires each woman to have a fair opportunity to understand the decision she is making.

Contraception

Contraception is one of the most common and personal areas in which women weigh pregnancy-prevention goals, health considerations, and individual preferences. Hormonal contraceptives, including oral contraceptive pills, may be used not only to prevent pregnancy but also to manage acne, PMOS, heavy or painful periods, and other health concerns. The reason for treatment should help shape the counseling and options considered.

Relevant considerations may include a woman's age, personal and family health history, previous blood clots, known thrombophilia, other medications, and lifestyle factors. Counseling should make these distinctions clear without presenting any method as universally right or universally wrong.

Informed contraceptive choice requires more than receiving a list of available methods. Women need an understandable comparison of benefits, risks, warning signs, and medically appropriate alternatives, along with the opportunity to ask questions and express what matters most to them. The goal is not simply method selection. It is a decision a woman understands and can make with confidence.

Contraceptive decisions should reflect each woman's health history, clotting risk, treatment goals, and preferences.

Blood clot information should be reinforced throughout pregnancy and after birth, when risk and care needs may change.

Pregnancy and the postpartum period

Pregnancy and the weeks after birth bring distinct changes in clotting risk. Care may involve obstetricians, midwives, nurses, primary-care clinicians, urgent-care professionals, and emergency teams. When information is fragmented across those settings, women may not know which symptoms are expected, which are concerning, or where to seek help.

Risk information should be reinforced at meaningful points, not delivered once and assumed to be remembered. Women need clear guidance about warning signs during pregnancy and after delivery, how long increased risk may remain relevant, and when symptoms warrant urgent evaluation. The postpartum period is demanding. Safety information should be designed for that reality.

Fertility treatment and IVF

Fertility treatment adds another dimension to women's hormonal health and clotting risk. Evidence suggests that pregnancies conceived through assisted reproductive treatment carry a higher risk of venous thromboembolism, although the absolute risk remains low for most women. Risk may be greater during early pregnancy and when treatment is complicated by ovarian hyperstimulation syndrome (OHSS).^{6,7}

IVF counseling should address individual clotting risk, warning signs, and circumstances that may require closer monitoring.

Women considering IVF should receive individualized information based on their personal clotting history, known thrombophilia, PMOS, treatment protocol, pregnancy, OHSS, and other relevant factors. Including IVF in blood clot education is not about portraying fertility treatment as broadly unsafe. It is about helping women understand when risk may change and when closer monitoring may be appropriate.

Better evidence should lead to better distinctions, not broader reassurance.

Perimenopause and menopause

The public understanding of menopause hormone therapy is changing, and counseling must keep pace. Current evidence does not support treating every form of hormone therapy, or every woman considering it, as having the same risk profile. Age, time since menopause began, personal health history, formulation, dose, and route of administration may all matter.

Oral systemic estrogen remains an important clot-risk consideration. Transdermal and low-dose local treatments may have different risk profiles. Recent regulatory changes also reflect a move away from broad, class-wide warnings and toward more specific benefit-risk discussions.⁸

The response to outdated or overly broad warnings should not be a new oversimplification. Women deserve a clear discussion of both benefits and possible risks. Decisions to begin, continue, change, or avoid hormone therapy should be based on current evidence and the individual rather than fear, dismissal, or a one-size-fits-all rule.

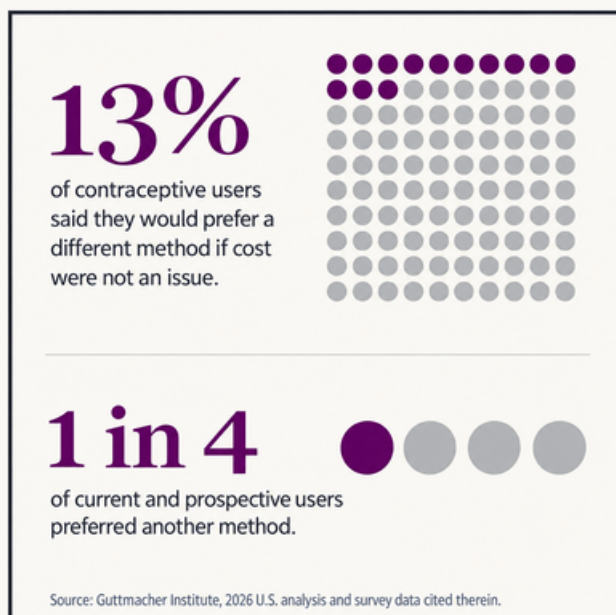
03 Give hormonal and nonhormonal contraceptive options a fair hearing

Younger women are asking more questions about hormonal contraception. Some are concerned about mood, sexual health, side effects, or the broader effects of medication on their bodies. Others are seeking information about nonhormonal contraception, fertility-awareness methods, and cycle tracking.

These questions are not a passing phase. They signal a change in what some patients want from contraceptive counseling. A 2025 peer-reviewed commentary described declining use of combined oral contraception in Western countries alongside greater interest in nonhormonal methods.⁹

Guttmacher Institute's 2026 U.S. analysis also documented varied method use and unfulfilled preferences. Thirteen percent of contraceptive users said they would prefer a different method if cost were not an issue; another national survey cited in the analysis found that one-quarter of current and prospective users preferred another method.¹⁰

These findings do not prove that hormonal contraception is unacceptable, and they do not make every online claim credible. They do show why patient concerns should be explored rather than dismissed.



A preference does not have to match a clinician's expectation to deserve a serious, evidence-based response.

When women do not feel heard in clinical settings, they may look elsewhere for answers. The better response is not to criticize the question. It is to offer a fuller, evidence-based conversation.

Nonhormonal methods are not interchangeable. Fertility-awareness methods differ from casual period tracking, and effectiveness varies.¹¹ Cycle-tracking tools can support awareness, but they can also collect sensitive reproductive-health data. Federal Trade Commission cases have documented fertility applications sharing health information with outside analytics or advertising companies despite privacy assurances.¹²

Women should be aware of the full range of medically appropriate options, along with the benefits, limitations, effectiveness, and privacy considerations that may accompany them. The goal is not to promote one method or product. It is to make informed choice possible.

04 Improve recognition and response when symptoms emerge

Prevention depends on more than what happens when a medication is prescribed or a risk factor is identified. It also depends on what happens when symptoms begin.

Blood clot symptoms, when they occur, can be subtle, change over time, or resemble other conditions. Patients may not recognize the urgency. Care teams may be less likely to consider a clot when a patient is young, appears healthy, or presents with symptoms that have several plausible explanations. In those moments, age and appearance can create false reassurance.

PCAG experiences repeatedly reflected the distance between having symptoms and understanding what they might mean. Closing that distance does not require testing every patient for every possible symptom. It requires keeping blood clots in the differential when symptoms, medications, recent pregnancy, health history, and other known risk factors warrant consideration.

A young and otherwise healthy appearance should not close the door on a clinically plausible diagnosis.

Urgent and emergency care

Urgent-care and emergency settings place significant demands on patients and care teams. Patients may not know that hormonal medication, recent pregnancy, surgery, travel, reduced mobility, a previous clot, or family history could be relevant. Pain, fear, and time pressure can make it difficult to give a complete history.

Women should not have to arrive with the correct diagnosis to have possible blood clot symptoms taken seriously.

Patients should not be expected to diagnose themselves. They can be better prepared to share relevant symptoms, medications, and health information. Care teams can strengthen safety by explaining what has been considered, what happens next, which changes require another evaluation, and when or where to seek further care.

Research involving patients and frontline emergency professionals has identified communication, coordination, and patient involvement as important parts of diagnostic safety in emergency settings.¹³

These are not simply measures of a better experience. They are part of how information is gathered, understood, and acted upon.

Emerging diagnostic support

Hospitals are beginning to use and study artificial intelligence to identify patients at higher risk for venous thromboembolism, support imaging review, assist with pulmonary embolism risk stratification, and guide some ultrasound examinations. These tools may support earlier recognition and more efficient assessment, although adoption and evidence vary.¹⁴

AI cannot compensate for missing history, ignored symptoms, or weak clinical processes. It does not replace clinical judgment or a clear conversation with the patient. Its promise lies in helping care teams see important patterns sooner, and then acting on them responsibly.

SIGNS AND SYMPTOMS

What to look for

When they occur, the most common signs or symptoms of a blood clot may include:

BLOOD CLOT IN AN ARM OR LEG

- Swelling
- Pain or tenderness
- Skin is warm to the touch
- Skin may be red or discolored

BLOOD CLOT IN THE LUNG

- Difficulty breathing, shortness of breath
- Faster than normal or irregular heartbeat
- Chest pain, may worsen with a deep breath
- Unexplained cough or coughing up blood

What to do

Seek medical care as soon as possible if you experience the symptoms of a blood clot in your leg or arm. Call 911 or seek emergency care if you experience the symptoms of a blood clot in your lung.

05 Build patient voice into safer care

Feeling heard and taken seriously was one of the strongest themes in the PCAG discussions. Patients and families described symptoms that were minimized, attributed to another cause, or considered unlikely because of age or apparent health.

Patients bring knowledge that no test result can fully capture: what is new, what feels different, what is worsening, and what has changed from their normal state. Family members may notice changes or provide crucial information during a stressful encounter. That knowledge does not replace clinical assessment. It strengthens the clinical picture.

Listening is therefore more than a courtesy. It is a practical part of safer care. It can reveal missing information, challenge an early assumption, and help a care team explain why one course of action makes sense or why another does not.

Self-advocacy without misplaced responsibility

Patients benefit from knowing how to ask questions, describe concerns, keep a medication list, and seek another evaluation when symptoms change or worsen. Preparation can make healthcare encounters more effective. But self-advocacy has limits. A woman who is frightened, in pain, or unfamiliar with medical language should not have to know which test to request, insist on the right diagnosis, or find the perfect words before her concern is taken seriously. Advocacy can support care. It cannot be the safeguard on which care depends.

Clinical responsibility remains with the care team.

Self-advocacy should strengthen safe care, not compensate for gaps in it.

Recovery, families, and loss

A blood clot experience does not necessarily end when treatment begins. Survivors may face physical limitations, fear of recurrence, anxiety, and uncertainty about future health decisions. Follow-up care should recognize that recovery can be both physical and emotional.

Families also hold relevant knowledge. Bereaved parents may remember early symptoms, questions raised, and details they wish had been understood sooner. Their experiences cannot determine how another patient should be treated. They can reveal recurring gaps in awareness, risk communication, and response that deserve serious attention.

The experience of a survivor or bereaved family is not a clinical formula. It is evidence of where closer attention may be needed.

Patient and family voices should not be treated as an emotional addendum to the evidence. Used responsibly, they can help show where evidence and care are failing to reach the people they are meant to protect.

06 Put credible information within reach

Women look for health information before appointments, after receiving a prescription, when symptoms develop, and following a diagnosis. They turn to online searches, social platforms, peer communities, advocacy organizations, and personal stories. What they find may include valuable education and support, but its quality, accuracy, and balance vary widely.

Research examining online contraceptive content has identified incomplete, unbalanced, and inaccurate claims alongside useful information and firsthand experience.¹⁵



TikTok has become a particularly visible source of contraceptive information for younger audiences. Studies of popular TikTok videos have found that hormonal contraception is frequently discussed through negative experiences, side effects, and discontinuation. Content created by healthcare professionals tends to be more reliable, but it may receive less engagement than content from other creators.^{16,17}

These studies do not establish that TikTok causes women to begin, stop, or avoid a contraceptive method. They do show what women may encounter when they seek answers and why telling patients simply to avoid misinformation is inadequate. Credible sources must be understandable, current, candid about uncertainty, and responsive to the questions women are actually asking.

Lived experience does not replace clinical evidence. It shows where evidence, information, or care may not be reaching people.

Medical institutions and advocacy organizations also have a responsibility to earn trust. Information should distinguish well-established evidence from emerging research, acknowledge benefits and tradeoffs, and correct misinformation without belittling the concerns or experiences that led someone to search for answers.

The different roles of evidence and personal stories

Medical evidence and personal stories answer different questions. Research can describe risk, frequency, effectiveness, and clinical outcomes. A personal story can show how information was understood, what an experience felt like, which warning signs were missed, and what a patient or family needed at the time.

A story should not be used to establish another person's individual risk or replace medical guidance. Medical information should not be presented in a way that removes the people affected. Credible advocacy makes the role of each clear and uses both to ask better questions.

Bringing the insights together across care settings

The six priorities outlined above recur across women's health, but they should not erase important clinical differences. A contraceptive consultation is not an emergency visit. A conversation about acne or PMOS is not the same as one about fertility treatment and IVF, pregnancy, the postpartum period, or menopause. Each requires evidence and counseling suited to the decision.

What connects these settings is not a single risk profile. It is a shared standard for communication and care: clear information, attention to the individual, room for questions, and an understandable next step.

The setting changes. The need to make information usable does not.

In contraception and broader hormonal health, that may mean clarifying why a medication is being considered and discussing benefits, clotting risk, warning signs, and alternatives.

In fertility treatment and IVF, it may mean considering treatment protocol, personal risk factors, pregnancy, and the possibility of OHSS.

During pregnancy and after the baby is born, it may mean reinforcing symptoms and urgent-care guidance at more than one point. In perimenopause and menopause, it means distinguishing among formulations, routes, and individual risk rather than relying on broad conclusions.

In adolescent, student-health, urgent-care, and emergency settings, it means resisting the assumption that youth or apparent health makes a blood clot impossible.

Conclusion: From voices to practice

The six PCAG priorities are connected by one central idea: women need information and care they can use in real life.

That means risk communication that prepares rather than merely discloses. It means decisions that reflect the individual, including why treatment is being considered and which alternatives matter to her. It means recognizing that preferences are changing and responding with evidence rather than dismissal. It means taking symptoms seriously without requiring patients to diagnose themselves. And it means treating patient and family experience as a source of insight into where systems can improve.

The Rowan Foundation will use these insights to shape future patient-informed education and communication work in consultation with a growing and increasingly diverse community of patients, survivors, families, and clinical advisors. The purpose is not to suggest a single answer—or elevate a single experience as the patient experience. It is to raise the standard of the questions, information, and care that surround women's health and blood clot prevention.

Blood clot risk should not remain an abstract warning until a crisis occurs.

Women need information they can apply to their own decisions. They need warning signs they can recognize, options they can evaluate, and care that considers the full picture. Healthcare professionals need resources and systems that support individualized counseling, careful assessment, and clear follow-through. Patients and families need to know that their experiences can help improve what comes next.

No report can remove every uncertainty from women's healthcare. It can insist that uncertainty be handled honestly, that risk be communicated meaningfully, and that preventable gaps not be accepted as inevitable.

The goal is not fear. It is informed choice, earlier recognition, and safer care.

Method note

This patient- and family-informed communication brief reflects two in-depth, facilitated 2026 discussions with members of the Rowan Foundation Patient & Community Advisory Group. The group includes people with varied experiences of blood clots, women's healthcare, recovery, caregiving, and loss.

Discussion notes were reviewed for recurring themes. The six priorities presented here were developed from those themes and considered alongside selected medical, public-health, and health-communication literature. The literature provides context for specific statements; it is not intended to validate or "prove" every individual experience shared by PCAG members.

This brief reflects lived experience and is not clinical guidance or a representative study of all patients, families, or healthcare encounters. The PCAG's value lies in bringing multiple perspectives together, identifying shared themes, and continuing to broaden the range of voices that inform the Foundation's work.

Medical review

This report was reviewed for medical accuracy by Vian Nguyen, MD, FACOG, medical advisor to the Rowan Foundation.

Disclaimer

This report is provided for educational and informational purposes only. It is not a substitute for individualized medical advice, diagnosis, or treatment. Questions about blood clot risk or symptoms, contraception, fertility treatment or IVF, pregnancy, the period after birth, perimenopause or menopause, hormone therapy, thrombophilia testing, or other health concerns should be discussed with a qualified healthcare professional or medical care team. Seek immediate medical attention for symptoms that may indicate a medical emergency.

Acknowledgments

The Rowan Foundation extends its appreciation to the members of its Patient & Community Advisory Group for contributing their time, experience, and thoughtful guidance. The depth and candor of their participation, and their willingness to speak about survival, recovery, healthcare experiences, and the loss of loved ones, shaped every section of this report.

The Foundation also recognizes the healthcare professionals, researchers, advocates, patients, and families working to improve blood clot awareness, informed decision-making, diagnosis, treatment, and support.

About the Rowan Foundation

The Rowan Foundation is a nonprofit organization dedicated to improving awareness of blood clots connected to women's health. Its work focuses on helping women understand risk, recognize possible symptoms, consider their options, and take part in informed conversations with their healthcare teams across contraception and other hormonal treatments, fertility care, pregnancy, and menopause.

The Foundation was created in memory of Alexandra Rowan, who died at age 23 from a pulmonary embolism associated with estrogen-containing contraception. Her life and legacy, and those of all women who have been affected by blood clots, continue to guide the Foundation's commitment to informed choices and safer paths for women.

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