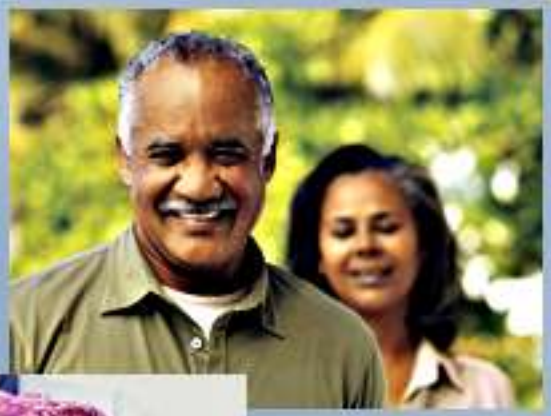
Patient Advocate Foundation

Solving Insurance and Healthcare Access Problems | since 1996



An Introduction to the Patient Advocate Foundation

…. An overview of programs and services

Presented by Erin Moaratty, Chief of External Communications Fanconi Anemia Research Fund

Monday, June 28, 2010

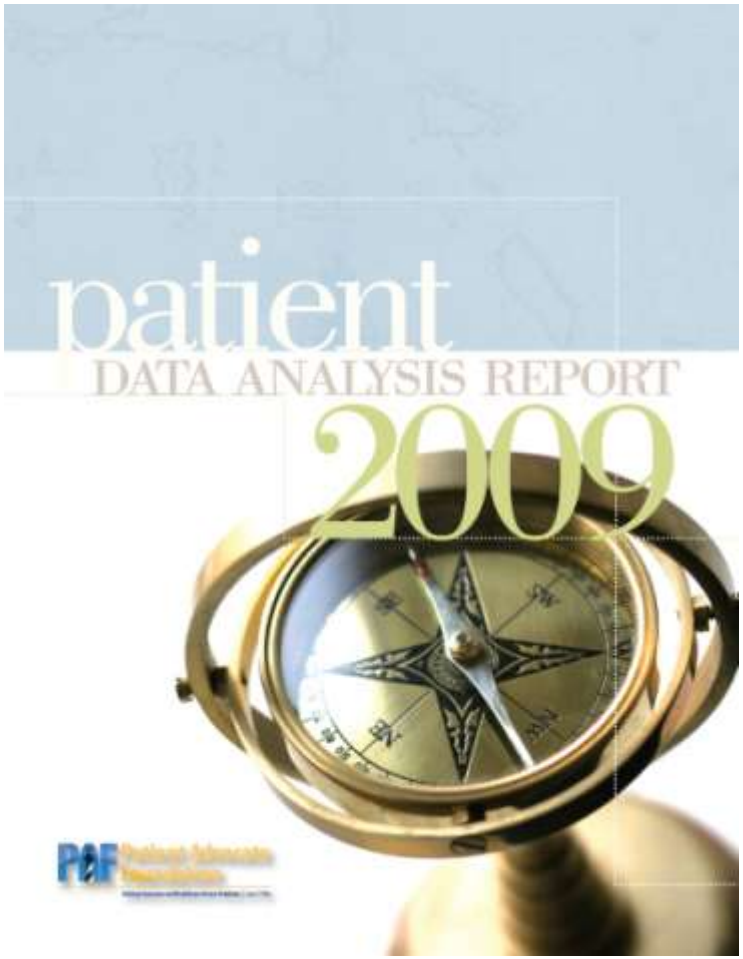
Who is PAF?

Patient Advocate Foundation is a national non-profit, direct patient services organization founded in 1996 that provides professional case management assistance to patients diagnosed with chronic, life-threatening/debilitating conditions assuring access to care, maintenance of employment and preservation of their financial stability.

PAF Programs

- Direct Case Management
- Centers for Disease Control Program to Increase Cancer Survivorship in Underserved Populations (SCUP)
- Centers for Disease Control Hematologic Cancer Education and Outreach Program
- LAF Survivor*Care* Partnership
- Co-Pay Relief (CPR), A Patient Assistance Program
- Colorectal CareLine (CCL)
- Virginia Cares Uninsured Program (VCUP)

Many Voices



It is through the experiences relayed by the patients we serve and the extensive documentation recorded by PAF throughout the service process that we are able to create the Annual Patient Data Analysis Report (PDAR)

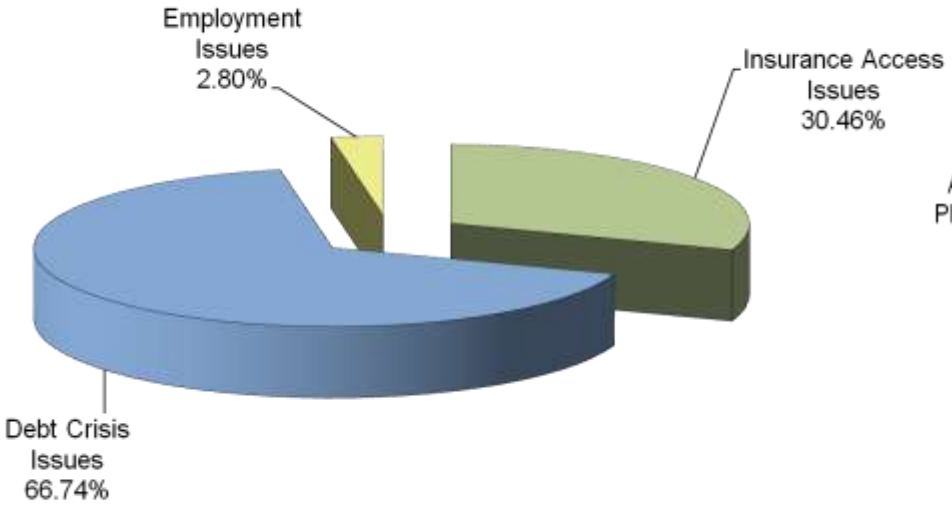
Summary of Patient Services:

2009 Patient Data Analysis

- **Total 2009 Case Count: 55,384**
- **Total Case Contacts: 685,521**
- **Webpage Views: 3,169,037**
- **Total Subscribed emails: 162,373**
- **Total 2008 PAF Contacts to Achieve Case Resolution: 407,111**

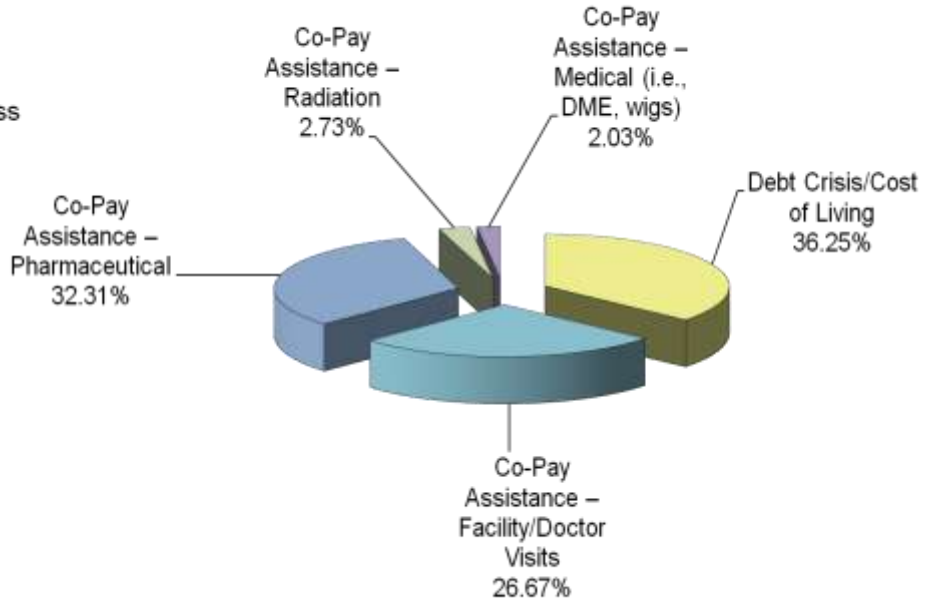
PAF Mission Analysis and Debt Crisis

PAF Mission Analysis in 2009



* Data reflects a compilation of issue codes from PAF's 3 major service categories only

PAF Debt Crisis Issue Analysis in 2009



* These figures represent the subcategories used in the "Debt Crisis Issues" category on the "PAF Mission Analysis in 2009" chart.

Globally, 66.74% of all patients contacting PAF in 2009 reported debt crisis issues as the primary concern.

The PAF Debt Crisis Issue Analysis graph provides a breakdown of the subcategories represented in the PAF Mission Analysis.

A Patient's Journey

PAF specializes in mediation, negotiation and education on behalf of patients to resolve problems in the following areas:

- Resolving debt crisis issues related to diagnosis
- Negotiation of access to pharmaceutical agents, chemotherapy, medical devices,
  surgical procedures
- Negotiating pre-authorization approvals and resolutions to coding and billing errors
- Providing assistance in expediting applications for Supplemental Security Income
  (SSI) and Social Security Disability Insurance (SSDI)
- Resolving enrollments in insurance issues in the public and private sectors
- Coordinating benefits among agencies, non-profits, and federal and state programs
- Providing assistance in expediting appeals process for insured patients
- Negotiating insurance coverage for clinical trials and emerging therapies

MEDIATE
ARBITRATE
NEGOTIATE

Know Your Insurance Policy

- Read the insurance plan document
- Understand the type of policy you are dealing with
    - Group- HMO/PPO
        - Fully Funded
        - Self Funded/Self Insured
        - State/Federal plan
    - Individual
- Review "Covered Benefits"
- Review "Non-Covered Benefits"
- Review "Exclusions"

Insurance (cont)

- Are there monetary limits on the policy?
  - Life Time maximums
  - Deductible
  - Co-Pays
  - Co-Insurance
  - Out of Network costs
- Is there a limit on specific benefits?
  - Home Health
  - Outpatient Therapy
  - Transplant Coverage
  - Visits vs Monetary caps

Things to watch for in the Policy

- "Older" policy language may not provide coverage for state of art treatments
- Treatment must be FDA approved
- Experimental /Investigational or off label treatments excluded
- Specialty treatment must be provided at center of excellence
- Clinical trials must be phase II, III or IV for coverage** (refer to plan language)

Dad on a journey . . .

Our lesson in times like these is to cope and to mourn, but not to be sad. Our mission in times like these is to show our loved one we will be okay, we will remember the good times and continue on their traits and qualities and use these to help complete our Journey. Let him off the ladder for he has been on a short but fulfilled Journey and has earned his praise. Now we praise him in our thoughts and prayers.

God Blessed Him…and will continue to Bless us

By Corey Crusoe

COBRA

Consolidated Omnibus Budget Reconciliation Act:

- Provides workers and their families who lose their health benefits the right to continue group health benefits provided by their employer for a limited time under certain circumstances:
  - voluntary or involuntary job loss
  - reduction in the hours worked
  - transition between jobs
  - death, divorce, and other life events

COBRA (cont)

- Qualified individuals may be required to pay the entire premium for coverage up to 102 percent of the cost to the plan
- You have 60 days to elect COBRA coverage
- If premiums are not paid by the first day of the period of coverage, the plan has the option to cancel coverage

COBRA Coverage for the Disabled

- The consumer is responsible for notifying the COBRA carrier once disability status has been awarded by Social Security Administration.
- You must notify the carrier of the disability determination within 60 days of receiving the award letter to be eligible for the 11 month extension

HIPAA

Health Insurance Portability & Accountability Act:

- Limits exclusions for preexisting conditions but does not **eliminate** all exclusions
- Prohibits discrimination against employees and dependents based on their health status
- Guarantees renew-ability and availability of health coverage to certain employees and individuals
- HIPAA does NOT replace the State as the primary regulator of health insurance

Healthcare Reform

ENACTED

Health Care Reform

The House of Representatives passed historic and transformative health care reform legislation late on March 21st. The House voted 219-212 approving legislation passed by the Senate in December 2009. After approving the Senate bill, the House adopted a package of changes (the reconciliation bill) to it by a vote of 220-211. The reconciliation bill moved to the Senate where slight changes were made necessitating another vote in the House to complete this legislation. The House passed the Senate reconciliation changes on March 25th by a vote of 220-207 and the bill was signed into law by President Obama on March 30th. Below are key provisions that will take effect within six months of passage.

Immediately

- Implementation of CER entity and appropriations
- Establish approval pathway and reimbursement for follow-on biologics
- State Ombudsman set
- Increase Medicaid drug rebate from 15.1% to 23.1%
- Require Medicaid rebate for new product formulations
- $250 rebate for Medicare beneficiaries that reach "the doughnut hole"

Ninety days after Enactment

- Establishes temporary high-risk pool(s) for people with medical conditions that make them uninsurable to get coverage
- Help for early retiree's through creation of a temporary re-insurance program

Six Months After Enactment

- Requires coverage of adult children up to age 26
- Prohibits preexisting condition exclusions for children under 19
- Prohibits health plans from placing lifetime caps on coverage & tightly restricts annual limits on coverage
- Requires coverage for preventive care with no co-payments
- Bans rescissions by health plans
- Establishes new, independent appeals process

Disability Criteria

- Disability as defined by Title II or Title XVI of the Social Security Act: "an individual must have an impairment or a combination of impairments that preclude substantial gainful activity that is expected to last a **continuous period of 12 months or longer or that is expected to result in death"**.

Compassionate Allowance

- Social Security has an obligation to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards.
- There are currently 88 conditions in which a patient would automatically qualify for social security disability.

Federal Disability Programs

SSDI (Social Security Disability Income) is a disability program for individuals:

- Who are deemed disabled and
- Have earned sufficient work credits
- Monthly payments are based on an individual's earnings records

SSI (Supplemental Security Income) is designed to help aged, blind and disabled people:

- Must be deemed disabled but do not have do not have sufficient work credits to qualify for SSDI
- Must meet income and assets guidelines
- If collect $1 in SSI and may be able to qualify for Medicaid

Medicaid

A Federally mandated health care program for people with low incomes and limited resources

- Each state determines eligibility and benefits that will be offered
  - Must meet income and asset requirements
- Must meet a qualifying "category"
  - Blind, aged, disabled or pregnant
- In most states, if you receive SSI payments you may qualify for Medicaid

Notice of Award Letter

- Serves as notification that Social Security Administration has determined you are disabled

- Two important terms:
  - ***Deemed:*** the date your disability is officially recognized
  - ***Entitled:*** the date on which you can actually access benefits

Benefits

- SSDI recipients begin receiving payments after 5 full months of disability.
  - SSDI recipients are entitled to Medicare coverage 24 months after the **entitlement date**.
  - It actually takes **29 months** from the date you are **deemed disabled** until you are eligible for Medicare coverage, not 24 months.

Medicare

- **Federal health insurance program for people age 65 or older and for people who have been getting Social Security disability benefits for at least two years**
  - Medicare Supplemental Policy (Medigap)
    - Enroll during open enrollment period, guarantee issue rights ensure penalty for pre-existing conditions
  - If you have Medicare before age 65 due to a disability
    - **Federal law** doesn't require insurance companies to sell Medigap policies to people under age 65
    - Some **states** require insurance companies sell you a Medigap policy, even if you are under age 65
  - Contact State Health Insurance Assistance Program

Disability Denials

- Up to 60% of all new disability applications are denied upon first review
- The average time for initial disability determination is 90-120 days
- Do not file a new application after a denial, appeal the original decision
- SSDI benefits can be paid retroactively up to a year from the date of official disability

Children with Disabilities

A child must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must have a physical or mental condition, or a combination of conditions, that results in "marked and severe functional limitations"
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death
- The child must not be working and earning more than $980 a month in 2009
- **Parents income <u>is considered</u> when determining child's eligibility**

When a disabled child turns age 18

For disability purposes in the SSI program:

- A child is considered an 'adult" at age 18
- Only consider the "adult's" income and resources not family members
- Disability criteria for adults used to determine disability
- If child is **already receiving SSI** payments, a review of the child's medical condition will be completed during a one year period that begins when the child turns age 18
- If child was **not eligible for SSI** before their 18th birthday because of parent's income or resources, they may become eligible for SSI at age 18

SSDI benefits for adults disabled since childhood

The SSDI program pays benefits to adults who have a disability that began before they became 22 years old:

- SSDI benefit considered a "child's" benefit because it is paid on a parent's Social Security earnings record
  - For a disabled adult to become entitled to this "child" benefit, one parent:
    - Must be receiving Social Security retirement or disability benefits under Social Security; or
    - Must have died but have worked
- SSDI disabled adult "child" benefits continue as long as the individual remains disabled.
  - A child does not need to have worked to get these benefits.

Work Programs for Children with Disabilities

Under SSI:

- For SSI payment purposes, disabled students younger than age 22 and regularly attending school, may exclude $1,640 of their monthly earnings (with annual limit of $6,600 in 2009)

Under SSDI:

- An adult disabled before age 22 can get the same help with work expenses as a child with SSI (help with rehabilitation and training)
- Cash benefits may continue until the individual can work on a regular basis
- Medicare may continue for up to 93 months (seven years, nine months)

Work Programs for Children (SSI cont)

- With a Plan to Achieve Self-Support (PASS), a child who is age 15 or older can save some income and resources to pay for education and other things needed to be able to work.
  - The saved income and resources are not counted when figuring the SSI payment.
  - Medicaid coverage will continue even if your child's earnings are high enough to stop the monthly SSI payment as long as the earnings are under a certain amount
  - Benefits for Children with Disabilities- www.ssa.gov/pubs

Adult Ticket to Work Program

- You can explore your work options without losing your benefits (up to 9 months)
- You can easily return to benefits if you have to stop working - expedited reinstatement of benefits
- You continue to receive healthcare benefits
- You will not receive a medical continuing disability review (CDR)

Aging off of Parent's Policy

If child is over 18 (or as specified in the policy) and is not a full time student, they may be eligible for COBRA continuation coverage:

- Entitles child to remain on your plan as a dependant up to maximum of 36 months
- Be sure there is not a lapse of greater than 63 days between insurance coverage to avoid pre-existing condition
- Refer to your state department of insurance website to explore insurance coverage options in your state:
  - Individual policy
  - Guarantee Issue plans
  - Extension of COBRA eligibility
  - Secure full time employment with employer offering group insurance

Maintaining Financial Security

- Co-pay/co-insurance (medicines, doctor visits, medical facilities/services)
- In network
    - Out of pocket maximum
- Out of network
    - Usual and Customary fees
    - Balance billing
- Deductible assistance
- Employers electing policies with limited coverage/benefits to contain costs

When Health Insurance is not enough

Currently CPR assist with 20 Diagnosis

Co-Pay Relief may be the answer

- Breast Cancer
- Lung Cancer
- Prostate Cancer
- CIA/CIN
- Kidney Cancer
- Sarcoma
- Colon Cancer
- Lymphoma
- Cutaneous T-Cell Lymphoma
- Head and Neck Cancer
- Malignant Brain Tumors
- Pancreatic Cancer
- Multiple Myeloma
- Myelodysplastic Syndrome
- Osteoporosis
- Hepatitis C
- Pain
- Rheumatoid Arthritis
- Diabetes
- Autoimmune Disorders (ITP, UC, Crohn's, PA)

How the CPR Program Operates

- CPR enrollment process
- Who may contact the CPR program for assistance?
- Types of insurance accepted
- Reimbursement process

A Family is Served…

"How could we ever be able to show our gratitude for your program. The disease takes its toll both physically and emotionally. The help you gave to us helped so much on the financial burden. If there is anyone out there who needs this assistance, you are there to help. May God bless all of you to lighten our lives and bring a light of hope through this journey."

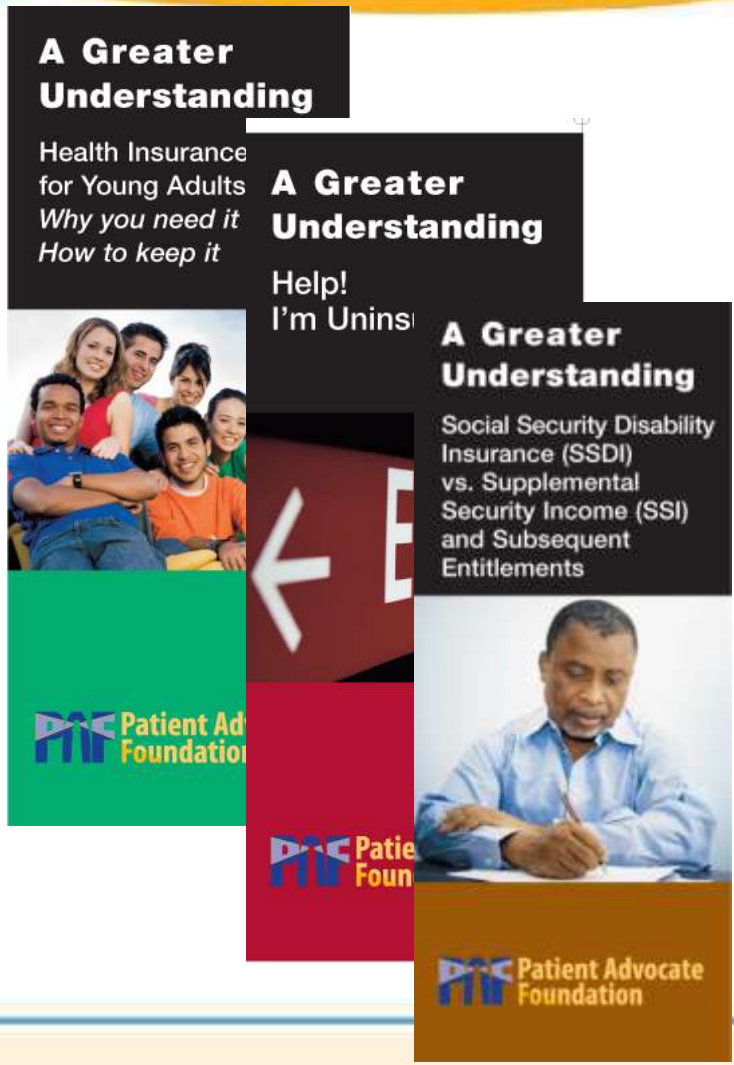
-Richard Tround

Kidney Cancer Patient

Tarpon Springs, FL

Patient Educational Opportunities
PAF Publications

- Your Guide to the Appeals Process
- The National Financial Resources Guidebook for Patients: A State-by- State Directory
- First My Illness, Now Job Discrimination
- Your Guide to the Disability Process
- Promoting a Healthier African American Community
- Too Young to be Ill… A Practical Survival Guide for Caregivers of Children and Young Adults
- Lighting the Way: A Practical Guide to Clinical Trials
- "*A Greater Understanding*" Pamphlet Series of 10 Pamphlets



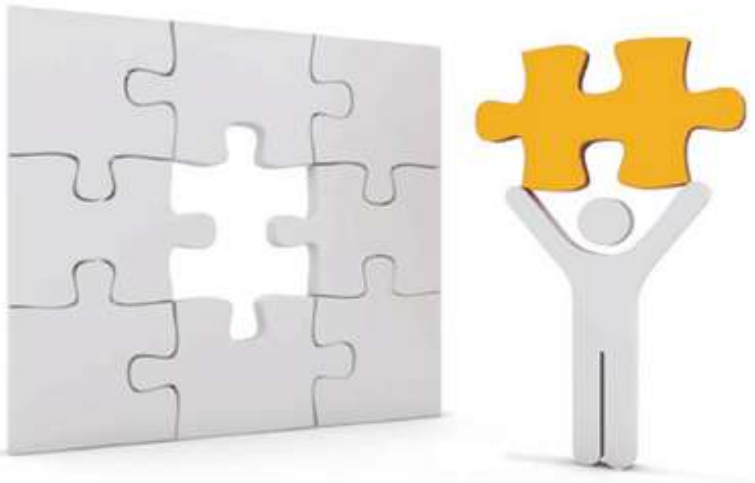
UNDERinsured…

"I am extremely thankful that someone told me about PAF. I called and they assigned me a professional case manager. The medical bills and co-pays were completely out of control, as though breast cancer wasn't enough to deal with. I needed someone to guide me in the right direction; it's a call I should have made months earlier. I received immediate response, concern for me! I had asked financial counselors at the hospital and doctors for indigent help as recommended by someone who took the time to care. The response I received was, "no they don't do that", no charity applications. I could fill out an application for financial aid, which I turned in with no response. I called PAF and had someone to help me move forward with debt crisis resolution. I notified the hospital financial counselors that I had contacted PAF and gave them my case manager's name and phone number, they refused to call. Within two weeks I had gotten a write off, approved at the hospital's Board meeting. I truly believe they approved help on my medical bills because I contacted PAF. I am happy to know who to call for assistance in the future. Thank you"

Alabama
Cheryl Jordan
Stage III Breast Cancer

The National Underinsured Resource Guide is intended to help underinsured individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement.

If you have health insurance but are still struggling to meet your out-of-pocket cost you would be considered ***underinsured***. To utilize our online National Underinsured Resource Directory click on "Get Help Now." You may search by using keywords or by completing the online interactive tool to help you ***find the missing pieces*** surrounding your particular situation. Initial results are available for review at any time. You will receive targeted resources the further you proceed through the question set.



UNDERINSURED?
FIND THE MISSING PIECES

PAF would like to thank the 2009 Patient Action Council committee for providing the opportunity to pursue this project and for its support and guidance throughout the entire process:

AMGEN Oncology
Lilly
NOVARTIS
Pfizer
sanofi aventis Because health matters

National Underinsured Resource Directory

“We just want to thank you for making the IMPOSSIBLE a reality. We can not thank you enough. We were told so many times that "there is no service where you live, so you can not take this baby home", end of story. What they didn't realize is that we would not take no for an answer and we would keep trying. You took the time to help us find a way home. You could have easily said, like many others, "we're so sorry, our hearts are with you, but there is no way." We have never felt such gratitude, as we did when we got word that we could come home, with Owen.

We are not even sure how we got hooked up with the right people, but however it happened we are so thankful. We just want you to know that we are thankful to you everyday and we appreciate all you did for our family. We know many hoops and loops have been jumped over and through, but again thank you! We hope that Owen has paved a way for other families to have their babies home and be able to stay in Wyoming, and not have to go through what we have gone through. This would not have been possible without you and we want to make sure you know that.

Love Owen's family

Contact Us

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Solving Insurance and Healthcare Access Problems | since 1996

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