



# **Patients' Rights Advocate Responsibilities: Outreach, Feedback, and Plans**

**Darrell Fisher  
Advisory Committee on the  
Medical Uses of Isotopes  
Rockville, Maryland  
October 20, 2010**

# **Patient concerns**

- **Best possible medical care when faced with illness and disease**
- **Access to latest scientific advances**
- **Protection from poor health care practices**
- **Good information; options for treatment**
- **To be treated with dignity and respect**
- **Long-term consequences of disease, including quality of life and financial impacts**

# **The patients' rights advocate**

- **A liaison between patients and health care providers to help improve or maintain a high quality of health care for patients**
- **An individual or organization**
- **Provides educational materials and counseling to help patients make wise choices**

***Usually non-profit, focusing on one aspect of health care or a specific disease.***

# **Who are the stakeholders?**

- **The uninformed public as patients and caregivers**
- **Hospital-designated (employee) advocates**
- **Patients' rights advocacy organizations**
  - **The National Patient Advocate Foundation (Washington, DC)**
  - **American Association of Kidney Patients (Tampa, FL)**
  - **National Breast Cancer Coalition (Washington, DC)**
  - **National Marrow Donor Program, Patient Advocacy Office (Minneapolis, MN)**

# **Stakeholders? (continued)**

- Breast Cancer Task Force, American Bar Association (Chicago, IL)**
- Patient Action Network, American Medical Association (Chicago, IL)**
- National Women's Health Network (Washington, DC)**
- National Hospice and Palliative Care Organization (Princeton, NJ)**
- American Pain Foundation (Baltimore, MD)**
- Coalition for Patients' Rights (Baltimore, MD)**
- National Association for Rights Protection and Advocacy (Phoenix, AZ) (mental health)**
- Us Too International**

# **Stakeholders? (continued)**

- **Fee-based organizations**
  - **Houston Patient Advocacy (Bellaire, TX)**
  - **RN Patient Advocates (Tucson, AZ)**
  - **AdvoConnections (Baldwinsville, NY)**
  - **The Karis Group (Austin, TX)**
  - **The Patient Advocate Foundation (Hampton, VA)**
  - **Coalition for Patients' Rights (Baltimore, MD)**
  - **National Association for Rights Protection and Advocacy (Phoenix, AZ) (in mental health)**
- **Individuals as patient counselors**

# **Regulation and patient access to health care**

**In a regulatory context, factors that impact patients' rights:**

- **Trade-offs between regulations that restrict availability or patient access to new treatments**
- **Slow process for new drug or device regulatory approval**
- **Regulations that restrict hospitals' and physicians' ability to provide most effective treatments**

# **Patients' Bill of Rights in Medicare and Medicaid (1997)**

- **Pres. Clinton created the Advisory Commission on Consumer Protection and Quality in the Health Care Industry**
  - **to promote and assure health care quality and value, and to protect consumers and workers in the health care system**
- **The President asked the Commission to develop a "Patients' Bill of Rights"**



# **Patients' Bill of Rights: goals**

- **Strengthen consumer confidence that the health care system is fair and responsive to consumer needs**
- **Reaffirm the importance of a strong relationship between patients and their health care providers**
- **Reaffirm the critical role consumers play in safeguarding their own health**

# **Federal statement on patients' rights**

- 1. The right to information...** to receive accurate, easily understood information needed to make informed decisions about health plans, facilities and professionals.
- 2. The right to choose...** health care providers; access to appropriate high-quality health care, including access for women to qualified obstetrician-gynecologists and for patients with serious medical conditions and chronic illnesses access to specialists.

# **Patients' Rights (continued)**

- 3. Access to emergency services... the right to emergency services when needed.**
- 4. Being a full partner in health care decisions... the right to participate in all decisions related to their health care.**
- 5. Care without discrimination... the right to considerate, respectful care, without discrimination based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.**

# **Patients' Rights (continued)**

- 6. The right to privacy... to communicate with health-care providers in confidence, with confidentiality of individually-identifiable health care information.**
- 7. The right to speedy complaint resolution... to a fair and efficient process for resolving differences with health plans, health care providers, and institutions that serve them.**

# **Patients' responsibilities**

- 1. Maintain good health.** In a health care system that affords patients rights and protections, patients must also take greater responsibility for maintaining good health.

**Source: Health and Safety Code Section 1288.4; 42 CFR 482.13, *Medicare Conditions of Participation* (64 Fed. Reg. 36070-36089, July 2,1999)**

# **Role of the ACMUI Patients' Rights Advocate**

- **Provide technical advice that helps the NRC develop useful and practical medical regulations (that are not overly burdensome)**
- **Provide technical assistance in licensing, inspection, and enforcement cases, if needed**

# **Role (continued)**

- **Provide consulting services to NRC staff when requested**
- **Bring key issues to the attention of NRC staff for appropriate action**
- **Be cognizant of the impacts of NRC actions on patient access to health care, and represent the concerns of patients' rights stakeholders**

# **Outreach**

- **The ACMUI Patients' Rights Advocate can also be a useful liaison between patients' rights advocacy organizations and the federal regulatory process**
  - **Limited to the medical use of radioisotopes in diagnostic and therapeutic medicine**



# **Organizations contacted**

- **Citizens for Medical Isotopes**
- **The Patient Advocate Foundation**
- **Us Too International Prostate Cancer Education/Support**
- **Fighting Children's Cancer Foundation**
- **Conservatives for Patients' Rights**

# Feedback

- **Most advocacy organizations are not familiar with the nuclear regulatory process and regulations that impact the use of radioisotopes in medicine**
- **Notable exception: Us Too International, which participated at NRC request in the most recent Commissioner's briefing (July 8, 2010)**

# **Feedback**

***“In relation to...requirements for reporting medical events with brachytherapy...it is important for doctors to use their clinical judgment to best treat the patient...”***

***“In closing, I would state that Us TOO would be happy to work through the NRC Advisory Committee Patient Rights’ Advocate...relating to issues that our organization has in regards to the use of medical isotopes.”***

**-- Dr. David Houchens, Columbus, Ohio**

# Plans

- **Continue outreach to patients' rights advocacy organizations**
- **Continue outreach to professional and scientific organizations involved in patient education and counseling**
- **Help organizations better understand the regulatory issues that affect patient access to best medical care**
- **Provide a meaningful liaison between these organizations and the NRC**

# **Summary and conclusions**

- **The most important elements of patient's rights are established in federal law**
- **The patients' rights advocate is an integral part of this NRC Advisory Committee**
- **Most patients, care givers, and rights advocacy organizations are not well informed on the medical isotope regulatory process**
- **The patients' rights advocate can provide a meaningful liaison between the NRC and patient advocacy organizations**