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Patient Advocacy Resources

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The following is a list of resources for anyone looking for help navigating the health care system including patients, family members, advocates, providers, and administrators. The organizations that are included offer services that range from advocating on national policy issues, to providing direct services to individuals in North Carolina, to improving communication within specific hospitals. This list is not exhaustive and is meant to provide examples of the types of resources available; if you are looking for specific help you may find that these organizations can refer you on to a more appropriate organization. Information presented here was obtained from each organization's website as well as through communications with organization representatives.

Consumers Advancing Patient Safety

Consumers Advancing Patient Safety (CAPS) is a national nonprofit organization focused on improving patient safety. Their website includes resources on how to improve communication between patients and providers.

<http://www.patientsafety.org>

Duke Health System Patient Advocacy Council and Volunteer Program

Duke's Patient Advocacy Council is made up of volunteers who meet regularly with hospital leadership with the goal of incorporating the patient's perspective in decision-making. The volunteer program consists of more than 250 undergraduate students at Duke University who each commit 40 hours per semester tending to patients' non-medical needs. These include reading to patients, bringing blankets, making sure meals are brought on time, and providing information about hospital and community services.

<http://www.dukehealth.org>

Financial Assistance

A number of organizations provide financial assistance to help patients with insurance premiums, deductibles, and copays. These include:

Caring Voice Coalition:

<http://www.caringvoice.org>

HealthWell Foundation:

<http://www.healthwellfoundation.org>

Patient Access Network Foundation:

<http://www.patientaccessnetwork.org>

Patient Advocacy Foundation Co-Pay Relief:

<http://www.copays.org>

Patient Services Incorporated:

<http://www.uneedpsi.org>

Exceptional Children's Assistance Center

The Exceptional Children's Assistance Center (ECAC) describes itself as "one of the oldest federally funded parent training and information centers in the world." Since 1983, ECAC has functioned as a parent-run resource for other parents, particularly parents of children with developmental disabilities. Their website contains information on how to receive training packets on up to 40 subjects, including attention deficit disorder, autism, and transition to adulthood. For more information on the ECAC and the work of their executive director, see page 92.

<http://www.ecac-parentcenter.org/>

Inclusive Health:

North Carolina Health Insurance Risk Pool

Created by the North Carolina General Assembly in 2007, the North Carolina Health Insurance Risk Pool (NCHIRP) provides access to health insurance for individuals with pre-existing medical conditions who face exceptionally high premiums in the individual insurance market and who do not have access to employer-sponsored health insurance. The health plan also provides resources to help individuals manage their own health.

<http://www.inclusivehealth.org>

Families USA

Families USA is a policy advocacy organization that describes themselves as the voice for health care consumers. Their website contains information and resources on children's health, Medicaid, Medicare, prescription drugs, the uninsured, and minority health. A section entitled "Resources for Consumers" provides information on obtaining coverage after losing a job as well as contact information for consumer assistance programs.

<http://www.familiesusa.org>