SMART ALACC
Adult Living After Childhood Cancer

Nombre: _____

MR#: _____

Survivor Summary

As a survivor, it is important that you keep a treatment summary and a copy of your care plan. You may want to create a file that also includes your healthcare provider's information and current medications (Visit www.oncolink.org/oncopilot for forms you can use to organize this material). While some survivors continue to see an oncologist or specialized survivorship provider, many return to a primary care provider or internist for routine care, many of whom are uncertain how to care for you. Developing the care plan can help you and your medical team understand what issues to look for, and how to handle them.

The list below can be used to track the recommended follow up care based on your treatments. You should use these as a guide to your cancer follow up care and discuss further with your physician.

You received the following treatments for Neuroblastoma

- Removal of Abdominal Tumor
- Cyclophosphamide (Cytoxan®, Neosar®)
- Topotecan (Hycamtin®)
- Abdominal Radiation
- Radiografía basada - IMRT [X-ray based radiation- IMRT]

Information from your oncology office

Risks Related to Surgery

Removal of Abdominal Tumor

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- Report any abdominal pain or chronic constipation.

Risks Related to Medications

Risk of Bladder or Urinary Tract Toxicities

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- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:
  - Pain when urinating

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- Urinary hesitancy (difficulty starting the stream)
- Urinary urgency or frequency
- Getting up in the middle of the night to urinate
- Blood in your urine

Risk of Developing Bladder Cancer

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- Avoid alcohol and smoking.
- Report the following symptoms to your healthcare provider:
  - Pain when urinating
  - Urinary hesitancy (difficulty starting the stream)
  - Urinary urgency or frequency
  - Getting up in the middle of the night to urinate
  - Blood in your urine

Skin Toxicities

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- Care for your skin with mild soaps and hydrating lotions.
- Protect your skin from sun damage.

Learning Differences

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- Let your healthcare team know if you have trouble with short term memory, multi-tasking, new learning, reading comprehension, working with numbers or a decrease in concentration ability that is affecting your day to day life.

Fertility and Sexuality Concerns for Male Survivors

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- Survivors wishing to father a child can obtain a semen analysis via their health care provider to assess their current fertility.
- Survivors dealing with other sexual concerns should seek the help of an urologist.

Risk of Developing a Secondary Cancer

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- There is a small risk of developing leukemia, myelodysplastic syndrome, lymphoma or other cancer years after your treatment is completed.
- The risk is higher in the first 10 years after your treatment.
- Report the following symptoms to your healthcare provider promptly:
  - feeling more tired or weaker than usual
  - looking pale
  - shortness of breath
  - loss of appetite
  - weight loss
  - chills, fevers, night sweats
  - painless swelling of a lymph node
  - easy bruising, nose bleeds, or bleeding from the gums
  - pain in your bones
- Consider having a complete blood count with differential checked by your healthcare provider if you experience any of the above symptoms.

Side Effects of Radiation

Long term effects of radiation therapy vary greatly depending on the areas included in the field of radiation and the radiation techniques that were used, as these continue to develop and improve. One issue that is consistent across all tissues is the possibility of developing a second cancer in or near the radiation field. Secondary cancers develop as a result of the exposure of healthy tissue to radiation. Newer radiation techniques are designed to limit this exposure, but it is not always possible to prevent all exposure and still achieve the desired outcomes.

Bladder Health

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- You should report any new or worsening bladder symptoms to your provider.
- You should avoid alcohol use and smoking as these can further irritate the bladder.

Maintaining Healthy Skin

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- You should use sunscreen anytime you are outdoors.
- You should see a wound care specialist or surgeon if you have any skin wound or ulcer that does not heal.

Your Spleen After Radiation

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- You should wear a medic alert bracelet stating that you have “asplenia” (no functioning spleen). You can get one from the MedicAlert Foundation.
- Notify your healthcare team right away if you develop a temperature greater than 100.4° F / 38° C or any signs of infection (sore throat, cough, burning with urination, ear pain, rash or shortness of breath).
- You should receive an annual flu vaccine as well as pneumococcal, Haemophilus influenza type b (Hib), meningococcal and hepatitis vaccines (per CDC guidelines).
- When traveling outside the U.S., speak with your provider to see if you need other vaccines or antibiotics.
- See your provider for any tick or animal bites.

Liver Health

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- Your provider will check your liver function before and after treatment with blood tests.
- You should have an annual exam by a healthcare provider to evaluate for liver disease.
- Do not drink alcohol, as it increases the risk of damage your liver.
- If you develop any symptoms of liver disease or abnormal testing results, you benefit from seeing a gastroenterologist.

Bowel Health

Puntos Clave

- You should seek immediate medical care for severe abdominal pain, especially if accompanied by nausea/ vomiting and constipation or for bleeding from the rectum or dark stools.
- Anti-diarrheal medicines can be helpful for chronic diarrhea.
- You should see a dietitian if you have unintended weight loss or nutritional deficits.
- Screening colonoscopy is recommended for all people beginning at age 50. For those who received abdominal radiation, screening colonoscopy is recommended beginning 10 years after radiation therapy (or at age 35, whichever is later), with repeat colonoscopy every 5 years.

Kidney Health

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- You should see your healthcare provider at least once a year for a physical, including screening for hypertension (high blood pressure) and diabetes mellitus.
- You should have blood work and urine testing to screen for kidney problems once a year.
- You should have good control of any high blood pressure or blood sugar as these can also damage the kidneys.

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- If you develop kidney disease, you should be seen by a nephrologist.

A Note on Fatigue

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- After making sure that fatigue is not being caused by another problem, find ways to best cope and manage the fatigue. Regular exercise, acceptance, and reprioritizing will help.
- Alert your healthcare provider if fatigue is worsening or a new symptom.

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